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**Pregnancy Interrupted: An Exploration of Miscarriage and
Primary Tokophobia**

Eleanor Gunn

This thesis is submitted in partial fulfilment of the requirements for the
degree of
Doctorate in Clinical Psychology

**Coventry University, Faculty of Health and Life Sciences
University of Warwick, Department of Psychology**

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List of Abbreviations

UK	United Kingdom (UK)
RCN	Royal College of Nursing
NICE	National Institute for Health and Care Excellence
NCCWH	National Collaborating Centre for Women and Children's Health
HCP	Healthcare professionals
C-section	Caesarean section
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-analyses
PTSD	Post Traumatic Stress Disorder
NCCMH	National Collaborating Centre for Mental Health
IPA	Interpretive Phenomenological Analysis
BPS	British Psychological Society

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Declaration

This thesis is an original piece of my own work and has not been submitted for any other degree or to any other institution. The thesis was carried out under the academic and clinical supervision of Ms. Jo Kucharska (Clinical Director in Clinical Psychology, Coventry University), Dr. Sarah Simmonds (Clinical Tutor in Clinical Psychology, Coventry University) and Dr. Kirstie McKenzie-McHarg, (Consultant Clinical Psychologist, National Health Service). Apart from the collaborations stated, all the material presented in this thesis is my own work. The literature review and empirical paper are written for submission to the: ***Journal of Reproductive and Infant Psychology***.

Summary

Pregnancy is a complex and unique experience, with many women facing challenges with their mental health during the transition to motherhood. It is imperative that knowledge in this area is expanded to ensure women are appropriately supported. This thesis informs understanding of experiences that interrupt the course of pregnancy in the context of miscarriage and primary tokophobia, a severe anxiety and fear of childbirth that presents before a woman gives birth for the first time.

Chapter one presents a systematic review of the qualitative literature exploring the psychosocial processes involved in miscarriage for women. Following database and bibliographic searches, thirteen studies were reviewed and included in the synthesis. Pregnancy was identified as promoting changes in women's identities which are important in understanding the impact of miscarriage. The process of recovery from miscarriage includes social, emotional, behavioural and cognitive processes, with many women experiencing change following the event. Differences between accounts are highlighted. A critique of the reviewed studies is provided, alongside the implications for clinical practice and future research.

Chapter two presents a qualitative research study that explores women's lived experiences of primary tokophobia. Using interpretative phenomenological analysis, the findings provide an in-depth account of women's experiences of navigating the conflict between their internal psycho-spiritual experiences and external social processes in the context of primary tokophobia. The findings are discussed in relation to implications for society, clinical practice and future research.

Chapter three offers a personal account of the author's experiences in conducting the research. From the researcher's constructivist position, it considers pertinent issues that arose during the research process, relating to power, responsibility and identity; reflecting on the personal and professional implications.

Overall word count: 19, 053

Chapter 1: Systematic review paper

An exploration of the psychosocial processes involved in women's experience of miscarriage: A systematic review of the qualitative literature

Written in preparation for submission to the: *Journal of Reproductive and Infant Psychology* (see Appendix A for author guidelines)

Overall word count (excluding tables, figures, footnotes and references): 7987

1.0 Abstract

Objective: The systematic review aimed to synthesise the qualitative literature to understand the psychosocial processes involved in miscarriage for women.

Background: Twenty-five percent of women experience miscarriage, however current understanding of the psychological and social consequences of pregnancy loss up to the 23rd week of gestation is limited.

Method: Thirteen papers were identified from: CINAHL Medline, PsychINFO, Scopus and AMED, in addition to bibliographic searches. Results were synthesised using interpretative thematic analysis.

Results: The psychosocial processes were identified in two primary themes: *Disputed Identities* and *Recovery*. Factors that influenced psychosocial processes were referenced (e.g. maternal age, unintended pregnancy) but were restricted by limitations with the included literature.

Conclusions: The development of identity in pregnancy is key in understanding loss experienced in miscarriage, with a number of emotional, cognitive and behavioural processes being involved in adjusting to the event. Policy change is discussed as a strategy in improving care and future research directions are considered.

Keywords: miscarriage, spontaneous abortion, psychosocial, women, qualitative

1.1 Introduction

1.1.1 Background

In the United Kingdom (UK) miscarriage is defined as, the unplanned spontaneous ending of pregnancy occurring from the date of conception until the end of the 23rd week of pregnancy (Royal College of Obstetricians & Gynaecologists, 2018; Rai & Regan, 2006). Based on this definition, it is estimated that 15 – 20 percent of all clinically recognised pregnancies result in miscarriage and that at least 25 percent of women will experience one or more spontaneous miscarriages (Rai & Regan, 2006). The experience of miscarriage is distinct to other losses arising from pregnancy, such as stillbirth or neonatal loss. Its occurrence before the 24th week of gestation means the foetus is not considered viable, thus currently there is no legal requirement for a certificate of birth, burial or cremation, making it a unique experience of death (Royal College of Nursing [RCN], 2015).

1.1.2 Clinical context

The National Institute for Health and Care Excellence guidance (NICE, 2012) recommends women experiencing early miscarriage, defined here as gestation loss up to 13 weeks, are treated with respect and offered appropriate emotional support (National Collaborating Centre for Women and Children's Health [NCCWCH], 2012). However, as routine psychological interventions have not been shown to be effective on measures of anxiety and depression for women who have miscarried pre-13 weeks gestation, with an absence of evidence reviewed post-13 weeks, NICE is unable to provide specific recommendations for emotional support beyond providing information (NCCWCH, 2012). Consequently, the most effective way to support individuals with miscarriage is currently not understood. This stance is

further supported by survey data from patients and healthcare professionals (HCP) alike, who have requested that research prioritises developing knowledge concerning the emotional and mental health implications of miscarriage (Prior et al., 2017).

1.1.3 Psychological and social consequences of miscarriage

The emotional experience of a miscarriage can be understood as consisting of internal psychological experiences and external social processes. Reviews of quantitative literature in this area have commonly identified that women experience increased symptoms of depression, anxiety and grief, reported to last between six and twelve months following the miscarriage (Brier, 2004, 2008; Geller, Kerns, & Klier, 2004; Klier, Geller, & Ritsher, 2002; Lok & Neugebauer, 2007). Further, due to methodological design and sampling concerns, inconsistent results regarding the importance of external factors (e.g. social support, the birth status of the women, age of women at gestation, impact of previous miscarriages and whether fertility difficulties are experienced) provide a lack of clarity regarding their contribution to the psychological impact of miscarriage (Brier, 2008; Geller et al., 2004; Klier et al., 2002; Lok & Neugebauer, 2007).

Moreover, whilst quantitative methods are useful in establishing the presence of a discrete set of psychological factors associated with miscarriage, limitations are posed by utilising this approach. A mixed-method study conducted by Lee and Rowlands (2015), revealed incongruent findings between quantitative and qualitative data. The quantitative analysis demonstrated an absence of long-term psychological consequences and found that once sociodemographic and lifestyle factors were controlled for, the reported levels of mental health difficulties in women with experience of miscarriage were comparable to women with no experience of

miscarriage. However, the qualitative analysis identified that women experienced a range of overwhelming emotions, disappointment in the social-support they received and found that the impact of miscarriage could be long-lasting in duration. The researchers alongside the NCCWCH (2012), suggest that quantitative data, while helpful in establishing patterns of psychiatric response to miscarriage, may fail to detect sub-clinical psychiatric symptoms. Furthermore, the quantitative data is unable to capture the nuanced experience of miscarriage including the complex interplay between social and emotional experiences (Lee & Rowlands, 2015).

1.1.4 Qualitative research

In response to the more recent growth in qualitative research in this area, Radford and Hughes (2015) synthesised the literature pertaining to women's experience of miscarriage occurring up to 16 weeks gestation and their experience of nursing care. It highlighted the type of support and emotional care women require from nursing staff, in addition to providing a broad overview of the associated 'negative' feelings and impact of the loss for women. There are a number of limitations to this work however, as the review did not provide full details of its search strategy, it included literature that did not fully meet its eligibility criteria and it failed to include a second-appraiser in its quality assessment process to determine inter-rater reliability. Subsequently its replicability and credibility as a systematic review were undermined (Booth, Sutton, & Papaioannou, 2016; Carroll & Booth, 2014). Furthermore, the full experience of miscarriage utilising the UK definition of up to 23 weeks, was not established. This is of particular importance, considering that research suggests that the separation of early and late experiences of miscarriage may be arbitrary when evaluating the psychosocial impact (Collins, Riggs, & Due, 2014).

1.1.5 Rationale

In order to improve support for women, it is necessary to develop a more comprehensive understanding of the psychological and social experiences involved in miscarriage, up to and including the 23rd week of gestation. Whilst a review of the qualitative literature does exist, it is not considered systematic and has limited scope in being primarily useful for those involved in nursing care (Radford & Hughes, 2015). Thus to-date, there exists a gap for an up-to-date methodologically robust systematic review of the qualitative literature, with a specific focus on providing an in-depth understanding of the psychosocial processes involved in miscarriage. This review will help broaden understanding in this area and subsequently make the knowledge accessible to a wider range of health and social care professionals that support women who experience miscarriage.

1.1.6 Aims

The aim of the current research is to systematically review and synthesise the existing qualitative literature to address the question: What are the psychosocial processes involved in miscarriage for women?

1.2 Method

1.2.1 Search strategy

1.2.1.1 Database searches

Ethical approval was gained from Coventry University (Appendix B). Following this, in April 2018 an electronic literature search was conducted of databases that were identified as appropriate for psychology and health-related topics. These included the: Cumulative Index of Nursing and Allied Health Literature (CINAHL),

Medline, PsychINFO, Scopus and Allied and Complementary Medicine Database (AMED).

Preceding the systematic search, the subject librarian and existing literature was consulted, to establish an appropriate search strategy within the databases. To ensure the most appropriate and inclusive terms were being used, database-specific thesaurus and keywords heading lists, such as Medical Subject Headings (MeSH), were utilised. Thus, search terms, truncations and boolean operators focussed on two key areas; these are displayed in Table 1.1.

Where the databases allowed, constraints were added to the databases to ensure the most relevant data was retrieved, in keeping with the inclusion and exclusion criteria displayed in Table 1.2.

Table 1.1: Search terms, truncations and boolean operators

Concept	Synonym and boolean operators
Miscarriage	Miscarriage OR abortion spontaneous OR abortion habitual OR pregnancy loss
Psychosocial	Psychosocial OR psychological OR psych* OR psychological adaptation OR psychological adjustment OR wellbeing OR psychological stress OR mental health OR emotion OR trauma OR resilience

1.2.1.2 Bibliographic search

A manual search was conducted on the reference list and citations of selected articles, to identify additional studies that may be appropriate.

1.2.2 Selection criteria

Table 1.2: Inclusion and exclusion criteria

Criteria	Inclusion	Exclusion
Miscarriage	Miscarriage < 23 weeks gestation Women with multiple experiences of pregnancy loss in addition to miscarriage	Pregnancy loss >24 weeks gestation
Gender	Female participants Studies where the experience of the woman who has miscarried was extractable	Studies where the experience of the woman who has miscarried was unextractable
Year of publication	Dated 2000 to 2018	Pre 2000
Age	Participants aged > 18 years	Participants aged <18
Language	Accessible in English	Non-English
Research design	Qualitative Mixed methods, where the qualitative contribution was extractable	Quantitative Mixed methods, where qualitative data was unextractable
Publication type	Full-text peer-reviewed published literature	Unpublished literature, abstracts, grey literature, academic theses.
Focus	Participants' experience of miscarriage, where psychosocial contributions were extractable.	Studies where the primary aims related to interventions for miscarriage; the experiences of others (e.g. HCPs) or care provision in miscarriage.

Studies included in the review were assessed to ensure they met the reviews eligibility criteria, full details of which are outlined in Table 1.2. To summarise, in keeping with UK criteria, miscarriage was defined as occurring up to the end of the 23rd week of gestation. Studies where participants experienced multiple pregnancy losses (e.g. stillbirth, abortion or neonatal death) were included if they had experience of at least one miscarriage, in recognition that women often experience multiple types of pregnancy loss (Rai & Regan 2006). The review aimed to focus on adult women's psychosocial experiences, thus where couples were sampled, the female's experience had to be identifiable and extractable to be included. Studies with a focus on additional primary aims were excluded. To ensure the review is clinically relevant and reflects the wide cultural diversity in the UK, no limits were set pertaining to the country of origin. However, only papers available in the English language were included to ensure access by the researcher.

1.2.3 Study identification

The identification and selection of studies were recorded using the "Preferred Reporting Items for Systematic Reviews and Meta-analyses" (PRISMA) flow diagram shown in Figure 1.1 (Moher, Liberati, Tetzlaff, & Altman, 2009). 373 articles were initially identified with a further four identified through manual searches. Following the removal of duplicates, the research title, abstracts and date of publication of 356 were screened to establish their suitability against the study's eligibility criteria. The majority of studies were rejected at this stage for being quantitative, not available in English, review articles, not related to miscarriage or focussed on intervention evaluation. This led to the full-text of 36 items being reviewed against the inclusion and exclusion criteria, with a further 23 being

excluded. Finally, 13 articles were deemed to meet the eligibility criteria and were included for review.

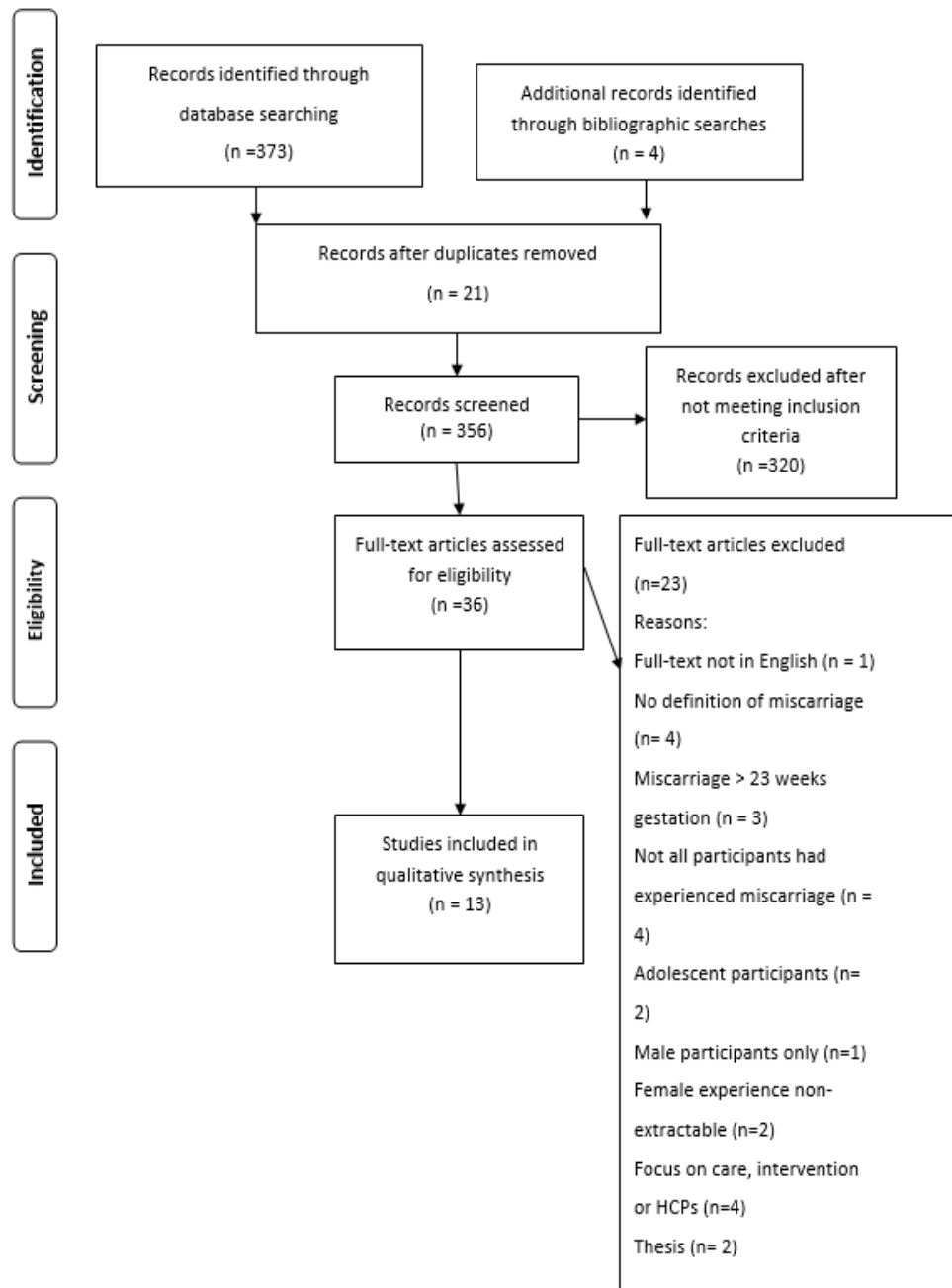


Figure 1.1: PRISMA screening procedure (Moher et al., 2009).

1.2.4 Quality assessment

A quality assessment framework was used to critically appraise the included studies. There is considerable debate regarding whether quality assessments should be completed in the context of qualitative reviews and if they are utilised, what their purpose should be (Carroll & Booth, 2014). It was decided a priori that all studies that met the inclusion and exclusion criteria would be included in the review. Therefore, a quality assessment was conducted for the purposes of transparency in highlighting the quality and methodological variations within the included literature. This assists with interpretation, with the aim of contributing to improving reporting standards in this research area (Kmet, Lee & Cook, 2004).

The current review has utilised the QualSyst, a systematic review framework developed by Kmet et al. (2004), due to its inclusion of a specific checklist to assess qualitative research (Appendix C). The checklist consists of 10-items that are given scores ranging from: 0 = “no”, 1 = “partial” and 2 = “yes”. The total for each study was calculated by adding the scores across the 10 items, with a maximum possible score of 20. A higher score is indicative of a higher quality paper.

1.2.4.1 Summary of quality assessment outcomes

Quality assessment scores ranged from between 12 – 18; these are illustrated in Table 1.3. Seven of the 13 papers were randomly allocated for review by an independent researcher to determine the reliability of the quality assessment. Inter-rater reliability analysis was performed using Kappa coefficients (Cohen, 1960). The individual Kappa coefficients are displayed in Table 1.3 (Please see Appendix D for raw data), ranging between 0.63 – 1.00, with an overall score across the papers of 0.82, which indicates very good agreement between the reviewers (Altman, 1999).

Full results from the quality assessment are detailed in Appendix E. Reference to the quality of papers will be embedded in the results section followed by a critique of their quality in the discussion.

1.2.5 Characteristics of included studies

Table 1.3 outlines the key characteristics of the studies included for review. The 13 studies reflected the experience of miscarriage in: Europe (United Kingdom $n=3$, Sweden $n=3$), USA ($n=2$), Canada ($n=1$), Australia ($n=1$), Israel ($n=2$) and Pakistan ($n=1$).

Overall the studies had an inconsistent approach to reporting their sample populations, with some studies failing to include data or provide sufficient detail beyond the eligibility criteria. For those that did include details: participants ages ranged between 21 and 47 years, with most participants included being identified as Caucasian or White and in relationships or cohabiting. Socio-economic status was mainly reported in terms of employment and education; with the majority of participants included being employed and having received some formal education.

Details concerning the samples' experience of pregnancy were particularly variable. Eight studies described the number of miscarriages experienced by participants, which ranged between 1 – 9 and the number of existing dependents participants had, which ranged from 0 – 8. Only three studies provided details pertaining to other types of perinatal loss. This inconsistent reporting has implications for the interpretation of findings as it limits the ability to draw comparisons between experiences reported in different studies.

The research design and methods of analysis were largely homogenous, with all using qualitative methods: nine studies used a phenomenological approach, two

studies used thematic analysis and two used inductive content analysis. There was consistency across methods of data collection with ten studies using semi-structured interviews. However, these varied significantly in duration, ranging from 12 minutes to 3 hours. Two studies utilised postal surveys. Additional details are included in Table 1.3.

Table 1.3: Characteristics of included studies

Author/Date/ country of origin	Study Aim	Research Design/Method of Analysis	Sample population	Method of data collection	Key Themes/Findings	Quality Assessment Score
Carolan & Wright, 2017 USA	To explore how women of an advanced maternal age perceive and describe their experience of miscarriage.	Phenomenological approach utilising a modified version of Moustakas analysis.	N: 10 women Age: 35-47 years ($M = 40.8$) Ethnicity: Caucasian ($n = 9$), Mexican-American ($n = 1$) Gestation at recent miscarriage: 1-20 weeks Duration since last miscarriage: < 2 years No. miscarriages: 1-6 Other pregnancy loss: Neonatal death ($n = 2$), still-birth ($n = 2$) Socio-economic status (SES): Middle-class and educated (no specific detail) Marital status: Married ($n = 9$) Dependents: 0-5	Semi-structured individual interviews. Duration: 39 – 108 minutes	Findings revealed two major essences 1) holistically grieving what was once there 2) search for meaning. Each essence contained four subthemes relating to physical, emotional, temporal and social contexts.	17/20 (Kappa = 1.00)

			Recruitment: Purposive- no further detail regarding where recruited.			
Meaney, Corcoran, Spillane, & O'Donoghue, 2017	To explore the experiences of those who have experienced miscarriage.	Interpretative Phenomenological Analysis (IPA)	<i>N</i> : 16 (<i>n</i> = 10 women, <i>n</i> = 6 men, 4 were couples) Age: inclusion > 18 years (no specific detail about participants age) Ethnicity: No detail included Gestation at recent miscarriage: 6 – 16 weeks Duration since previous miscarriage: 7 – 20 months No. miscarriages: 2 – 7 Other pregnancy loss: No detail included SES: No detail included Marital status: No detail Dependents: 0 - 3 Recruitment: Purposive, women recruited from a previous study and	Semi-structured individual interviews, Duration: 28 – 69 minutes.	Findings revealed six superordinate themes: 1) acknowledgment of miscarriage as a valid loss 2) misperceptions of miscarriage 3) the hospital environment and management of miscarriage 4) support and coping 5) reproductive histories 6) implications for future pregnancies.	16/20 (Kappa= 0.76)

			snowballing technique through charity.			
Batool & Azam, 2016 Pakistan	In-depth investigation of the psycho-social experiences of women after the first miscarriage of the first child, to understand the perspective of women in Pakistan.	IPA	<p><i>N</i>: 10 women Age: 23 – 29 (<i>M</i> = 24.9) Ethnicity: no detail included Gestation at recent miscarriage: 18 – 20 weeks No. miscarriages: 1 Duration since miscarriage: 6 – 10 months SES: Described as diverse- education length (<i>M</i>= 14 years) Marital status: Married (<i>N</i> = 10) for 2-3 years. Dependents: 0 Recruitment: Purposive recruited using snowball strategy through personal contacts</p>	Semi-structured individual interviews. Duration: 55 – 90 minutes.	Findings revealed six superordinate themes: 1) shattered planning 2) physical and emotional pain 3) reaction to miscarriage 4) transformed marital relationship 5) in-laws support 6) blame attributions	16/20 (Kappa = 0.76)
MacWilliams, Hughes, Aston, Field, & Moffatt, 2016	To explore the experiences of miscarriage in women who attended an	Interpretative phenomenology	<p><i>N</i>: 8 women Age: 21-36 years (<i>M</i>= 31) Ethnicity: No detail included</p>	Semi-structured individual interviews. Duration: 45 – 90 minutes.	Findings revealed five themes: 1) pregnant/life: miscarriage/death 2) deciding to go to the emergency department:	17/20

Canada	Emergency Department.		<p>Gestation at recent miscarriage: 5 – 14 weeks</p> <p>Duration since recent miscarriage: 1 month – 6 years</p> <p>No. miscarriages:</p> <p>Women with multiple experiences but no explicit detail.</p> <p>Previous pregnancy loss: Abortion, neonatal death (no specific detail included).</p> <p>SES: No detail included</p> <p>Marital status: No detail</p> <p>Dependents: No detail</p> <p>Recruitment: Purposive participants were given letter of discharge from Emergency department</p>		<p>something's gone wrong</p> <p>3) not an illness: a different kind of trauma</p> <p>4) need for acknowledgement</p> <p>5) leaving the emergency department: what now?</p>	
Andersson, Nilsson, & Adolfsson, 2012	To investigate how women in Sweden, who experienced one or more miscarriages, managed their	Inductive content analysis	<p>N: 13 women</p> <p>Age: > 18 years (no specific detail included)</p> <p>Ethnicity: No detail included</p> <p>Gestation at recent miscarriage: Defined as</p>	<p>Semi-structured individual interviews.</p> <p>Duration: 12 – 60 minutes</p>	<p>Findings revealed 5 categories: 1) distancing herself from the pregnancy 2) focussing on her pregnancy symptoms 3) searching for confirming</p>	17/20

	feelings when they became pregnant again (between 9 -12 weeks gestation)		22 weeks in inclusion criteria. Duration since recent miscarriage: No detail No. miscarriages: At least one but no additional detail. Previous pregnancy loss: No detail. SES: No detail included Marital status: No detail Dependents: No detail but all pregnant at interview Recruitment: Purposive – previous engagement in another study about miscarriage, asked to make contact if they became pregnant again.		information 4) asking for ultrasound confirmation 5) asking for professional and social support	
Adolfsson, 2010 Sweden	To identify and describe women's experience of miscarriage	Interpretative phenomenology – Heidegger's 'being in time'	N: 13 women Age: > 18 years (no specific detail included) Ethnicity: No detail included Gestation at recent miscarriage: < 16 weeks	Semi-structured individual interviews. Duration: 85 – 150 minutes	Findings revealed women's feelings and impressions of miscarriage were influenced by: past experiences of miscarriage, pregnancy and birth; present	12/20

			(no specific detail included) Duration since recent miscarriage: No detail included No. miscarriages: No detail included Previous pregnancy loss: No detail. SES: No detail included Marital status: No detail Dependents: No detail Recruitment: Purposive contacted those that had been treated for miscarriage at an emergency department.		conditions relating to work, relationship and living arrangements, and this influenced women's future hopes and expectations related to pregnancy and motherhood.	
Hamama-Raz, Hemmendinger, & Buchbinder, 2010 Israel	To gain a deeper understanding of the implications and meaning of spontaneous abortion among religious Jewish couples	Phenomenological approach	<i>N</i> : 10 participants, consisting of five couples (women <i>n</i> =5 and men <i>n</i> = 5). Age: 26 – 35 years (<i>M</i> = 30.5 years) Ethnicity: No detail included Gestation at recent miscarriage: 10 – 18 weeks	Semi-structured individual interviews. Duration: 2 hours	Findings revealed the nature of miscarriage is different for women and men. The results were described in five themes: 1) shock and isolation- the process of coping with spontaneous abortion 2) the meaning of the relationship with the foetus 3) questions	18/20

			<p>Duration since recent miscarriage: 2 months – 2 years</p> <p>No. miscarriages: No detail included</p> <p>Previous pregnancy loss: No detail included.</p> <p>SES: All in paid employment and educated past high school</p> <p>Marital status: All married between 4 – 14 years.</p> <p>Dependents: 2 - 6</p> <p>Recruitment: Purposive using snowball technique – unclear how recruited.</p>		<p>regarding motherhood 4) crisis in faith 5) the reconstruction of the couple's relationship.</p>	
<p>Gerber-Epstein, Leichtetritt, & Benyamini, 2008</p> <p>Israel</p>	<p>To observe the subjective experience of the woman who has miscarried a first and early pregnancy.</p>	<p>Thematic analysis</p>	<p><i>N</i>: 19 women</p> <p>Age: 25 – 35 (<i>M</i> = 30.6 years).</p> <p>Ethnicity: No detail provided</p> <p>Gestation miscarriage: 6 – 15 weeks</p> <p>Duration since recent miscarriage: 1 – 4 years</p> <p>No. miscarriages: 0</p>	<p>Active individual interviews</p> <p>Duration 1 – 3 hours</p>	<p>Findings revealed five themes: 1) the greater the joy, the more painful the crash 2) the nature and intensity of the loss 3) sources of support 4) life after the miscarriage 5) recommendations to professionals.</p>	<p>18/20 (Kappa = 1:00)</p>

			Previous pregnancy loss: No detail SES: Professionals with between 12 – 20 years in education Marital status: No detail Dependents: 1-3 Recruitment: Criterion sampling. Located through use of adverts and personal connections.			
Swanson, Connor, Jolley, Pettinato, & Wang, 2007 USA	To describe women's feelings over the first year of miscarriage To describe the changes in feelings over the first year of miscarriage To explore the influence of life contexts before and after loss	Longitudinal design/ inductive content analysis	N: 85 women Age: > 18 years Ethnicity: 95.2 % White Gestation miscarriage: < 20 weeks Duration since recent miscarriage: 1 – 3 weeks at study inception No. miscarriages: No detail included Previous pregnancy loss: Neonatal death, early and late miscarriage (no specific detail) SES: Years in education (<i>M</i> = 15.71)	Postal survey	The findings revealed three main responses: 1) healing 2) actively grieving 3) overwhelmed. Responses experienced one-week post-miscarriage were significantly less six- weeks post-miscarriage.	14/20

			<p>Marital status: Married or single (no specific detail included)</p> <p>Dependents: No detail included.</p> <p>Recruitment: Volunteer sample in response to advert or leaflet provided by obstetrician.</p>			
<p>Simmons, Singh, Maconochie, Doyle, & Green, 2006</p> <p>UK</p>	<p>To describe women's personal experience of miscarriage</p>	<p>Thematic analysis</p>	<p><i>N</i>: 172 Women</p> <p>Age: 25 - 40 (<i>M</i> = 31.4 years).</p> <p>Ethnicity: No detail included</p> <p>Gestation miscarriage: 8 – 23 weeks</p> <p>Miscarriages experience between: 1980 - 2002</p> <p>No. miscarriages: 1-3+</p> <p>Previous pregnancy loss: No specific detail included</p> <p>SES: No formal qualifications (<i>n</i>=5), GCSE or equivalent (<i>n</i>=59), A-level or equivalent (<i>n</i> = 38), degree or equivalent</p>	<p>Postal survey</p>	<p>The findings revealed four themes: 1) searching for meaning in miscarriage 2) justification of motherhood 3) medicalisation and the lived experience of miscarriage 4) support</p>	<p>15/20 (Kappa= 0.63)</p>

			(<i>n</i> = 68). Marital status: Married/living together (<i>n</i> = 153), other (<i>n</i> = 18). Dependents: 104 live births (no specific detail included). Recruitment: 2 stage, postal survey randomly selected from the electoral register.			
Adolfsson, Larsson, Wijma, & Bertero, 2004 Sweden	To identify and describe women's experience of miscarriage	Interpretative phenomenology	<i>N</i> : 13 women Age: <i>M</i> = 31.3 years Ethnicity: No detail included Gestation of recent miscarriage: 5 – 16 weeks Duration since recent miscarriage: 8 – 20 weeks No. miscarriages: 1- 5 Previous pregnancy loss: No detail included SES: Unemployed (<i>n</i> = 4), employed (<i>n</i> = 4) Marital status: married (<i>n</i> = 12), single (<i>n</i> = 1)	Semi-structured individual interviews Duration: 85 – 100 minutes	The findings revealed one major theme: guilt and emptiness With five additional sub- themes 1) feeling emotionally split 2) bodily sensation 3) loss 4) grief 5) abandonment	16/20 (Kappa = 1:00)

			Dependents: 0 – 8 Recruitment: Purposive – letters sent to women who attended an emergency ward.			
Maker & Ogden, 2003	To provide detailed insight into miscarriage experience in the first trimester	IPA	<p><i>N</i>: 13 women Age: 22 – 43 years (<i>M</i> = 34.4 years) Ethnicity: White (<i>n</i> = 10), Black-African (<i>n</i> = 2), other (<i>n</i> = 1) Gestation of recent miscarriage: 7 -13 weeks Duration since recent miscarriage: < 5 weeks No. miscarriages: 1 -2 Previous pregnancy loss: No detail included Dependents: No detail SES: Unemployed (<i>n</i> = 4), employed (<i>n</i> = 4) Marital status: married (<i>n</i> = 12), single (<i>n</i> = 1) Dependents: 0 - 2 Recruitment: Purposive – recruited during attendance at an early pregnancy unit.</p>	Semi-structured individual interviews Duration: 30 – 60 minutes	Findings identified a range of themes which were categorised into three stages. 1) Turmoil – comprising of shock, feeling unprepared and denial. 2) Adjustment – comprising of social comparisons, sharing and finding meaning 3) Resolution – comprising of a decline in negative emotions, seeing miscarriage as a learning experience and an assessment of miscarriage in the past and future.	14/20

Harvey, Moyle, & Creedy, 2001	To explore women's experience of early miscarriage	Phenomenological approach (Colazzani's method)	<i>N</i> : 3 women Age: 24 -35 years (<i>M</i> = 32.3 years) Ethnicity: No detail Gestation of recent miscarriage: 6- 11 weeks Duration since recent miscarriage: < 12 months No. miscarriages: 1-9 Previous pregnancy loss: No detail included SES: unclear Marital status: Married (<i>n</i> =2), no detail (<i>n</i> = 1) Dependents: 0 - 2 Recruitment: Purposive – recruited through a newspaper advert.	Unstructured open-ended interview Duration: 60 minutes	The findings revealed early miscarriage was a negative experience and symbolised the loss: of a baby; the role of motherhood and, hopes and dreams. Themes identified focussed on: loss, uncertainty, guilt, clinical care and need for emotional support.	17/20 Kappa = 0.63
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1.2.6 Analysis

There is a lack of consensus concerning the most appropriate method to synthesise qualitative findings, with there being a significant overlap between different approaches (Barnett-Page & Thomas, 2009; Booth et al., 2016; Melendez-Torres, Grant, & Bonell, 2015). Given the aim of qualitative synthesis is to move beyond the original data, an interpretative thematic synthesis was conducted (Britten et al., 2002; Thomas & Harden, 2008). This method seeks to identify the range of factors that are pertinent for understanding a phenomenon and then organises these into interpretative themes (Barnett-Page & Thomas, 2009; Booth et al., 2016). The synthesis was guided by the method described by Thomas and Harden (2008) relating to coding, developing descriptive themes and analytical themes. The process is detailed in Table 1.4.

Table 1.4: Stages of interpretive thematic analysis

Stages	Description
Coding	The results section from each study was read. To enable the translation of concepts between studies, where appropriate whole themes or individual parts of the text were coded in relation to the research aims.
Developing descriptive themes	The coded data was organised into descriptive themes, which was achieved by identifying similarities and differences between codes.
Developing analytical themes	Descriptive themes were combined, and theme titles adapted; this led to the emergence of analytical themes. Overarching themes were identified to further interpret the data in the context of the research aims.

1.3 Results

The results revealed two main overarching themes; *Disrupted identities*, which contained two subthemes and *Recovery*, which contained five subthemes.

1.3.1 Theme 1: Disrupted identities

This theme describes women's internal changes in pregnancy and how these adaptations are reversed in the event of a miscarriage. It consists of two sub-themes: *Adapting in pregnancy* and *Deconstruction in miscarriage*.

1.3.1.1 Adapting in pregnancy

Across all studies 'happiness' was referenced, by some participants, in pregnancy. In addition to this, eight studies of varying levels of quality, made reference to the cognitive and behavioural adjustments involved in pregnancy (Harvey et al., 2001; Adolfsson et al., 2004; Adolfsson, 2010; Gerber-Epstein et al., 2008; Hamama-Raz et al., 2010; Batool & Azam, 2016; MacWilliams et al., 2016; Andersson et al., 2012).

These adjustments triggered a variety of developments in women's self-identities and the identity of the foetus. In a high-quality study, Carolan and Wright (2017) found that women derived their femininity from being able to "*become pregnant*". Further, Harvey et al. (2001) found that this process began as soon as women conceived, with pregnancy providing meaning to concepts of motherhood and family.

Additionally, six studies detailed the way women constructed their new identities, focusing on the imagined future of the mother, foetus, and the family unit (Adolfsson

et al., 2004; Adolfsson, 2010; Gerber-Epstein et al., 2008; Hamama-Raz et al., 2010; Batool & Azam, 2016; MacWilliams et al., 2016).

For example, MacWilliams et al.'s (2016) high-quality study, illustrated how the cognitive processes could be both unconscious and spontaneous:

“...you’re automatically in dream-world...what’s this going to amount to...who is this person forming inside of me?”

(Isabel, p.506).

Identity was further constructed through imagination as women began to form a strong bond and attachment to the foetus. The attachment-relationship was described as “*tangible*”, with a participant conceptualising the foetus as a “*meaningful creature*” and a “*child*” (Hamama-Raz et al., 2010). Similar findings were reported by other studies’ (Adolfsson et al., 2004; Batool & Azam, 2016; Gerber-Epstein et al., 2008).

Batool and Azam’s (2016) study, which exclusively included participants with later experiences of miscarriage (18-20 weeks), described how the identity of the baby was built by physical action.

“...we did a lot of shopping for a baby girl...we had a huge collection of baby stuff by the end of our second month. We had even finalised the name of our baby.”

(Safina, p.640)

This may suggest more concrete steps are taken to bond with the foetus as the pregnancy becomes increasingly established.

In contrast, Andersson et al. (2012) whose sample only included participants who were currently pregnant, found women actively engaged in avoiding thinking about the future of the foetus, to protect themselves from further miscarriage.

1.3.1.2 Deconstruction in miscarriage

For many women, their miscarriage represented a deconstruction of the changes established in pregnancy.

Three studies, explicitly referred to the destruction caused by miscarriage in their theme titles “*The Greater the Joy the More Painful the Crash*” (Gerber-Epstein et al., 2008), “*Shattered Planning*” (Batool & Azam, 2016) and “*Miscarriage/Death*” (MacWilliams et al., 2016).

Four studies described how the loss of the imagined child accompanies the biological expulsion of the foetus (Carolan & Wright, 2017; Gerber-Epstein et al., 2008; Adolfsson et al., 2004; Hamama-Raz et al., 2010) For example:

“...I would look into the toilet bowl and imagine the foetus’s hand, and its head...the child...it’s a sad experience...there was something there.”

(Hamama-Raz et al., 2010, Woman from couple 5)

However, for some women emotional pain was felt because there was no certainty or realisation of who they were grieving for, with the imagined child never being embodied (Carolan & Wright, 2017; Gerber-Epstein et al., 2008). It is evident that some women had established strong attachments to the foetus, with women in two studies describing that they had lost a “physical” part of themselves in the miscarriage (Adolfsson et al., 2004; Gerber-Epstein et al., 2008).

Four studies detailed how a woman's sense of identity was fundamentally challenged by miscarriage (Hamama-Raz et al., 2010; Carolan & Wright, 2017; Batool & Azam, 2016; Harvey et al., 2001). This was exemplified by women's beliefs about their failings as a mother and wife, which led to feelings of "*emptiness*" and "*isolation*", (Hamama-Raz et al., 2010).

Harvey et al. (2001), in a high-quality study, described this in the context of the loss of the mother-to-be-role. The authors attributed some of the distress to society's failure to acknowledge the experience of motherhood in women with miscarriage. This finding was echoed in Carolan and Wright's (2017) study where participants also experienced changes in identity by disputing their previously assumed "*femaleness*" in the context of their biological capabilities:

"it makes you feel less of a woman because you can't do what your body was designed to do."

(Stacey, p149).

With this finding being unique to this study, it may be reflective of the older maternal age of the participants included and their context of multiple pregnancy losses.

Women's future hope for their motherhood identity was eroded by concerns about their ability to conceive. Studies that detailed the cognitive process behind these concerns identified that women thought there was something physically wrong with them or that their increasing age would act as a barrier (Maker & Ogden, 2003; Adolfsson, 2010, Gerber-Epstein et al., 2008; Meaney et al., 2017). For a participant of Meaney et al.'s (2017), this manifested in the context of recurrent miscarriages:

“We already had a loss, I know they were two different losses, but I was thinking not again, what is going on, is there something wrong with me...”

(P1, p.5).

Swanson et al. (2007), found that women typically started to feel deprived of motherhood one year following the event, due to being unable to ‘mother’ the baby they had lost.

1.3.2. Theme 2: Recovery

This theme draws together the internal and external processes experienced as women recover from their miscarriage. It encompasses the subthemes: *The mind-body connection, cognitive appraisals, emotions: active grief, interpersonal connections and what is left...*

1.3.2.1. The mind-body connection

Eight studies denoted how the physical aspects of miscarriage are associated with the psychological processing of the event (Adolfsson et al., 2004; MacWilliams et al., 2016; Adolfsson, 2010; Carolan & Wright, 2017; Maker & Ogden, 2003; Batool & Azam, 2016; Andersson et al., 2012; Simmons et al., 2006).

Two of the lowest quality papers, described how some women engaged in “*denial*” about their miscarriage until it was confirmed medically by an ultrasound, despite the presence of physical symptoms of miscarriage (Adolfsson, 2010; Maker & Ogden, 2003). Subsequently, this triggered emotional and cognitive acknowledgment of the loss.

A participant described her internal processes (Maker & Odgen, 2003):

“[I was thinking] ...don’t let this be happening, and as I say right up until the moment of the scan, even though it was fairly obvious that this was it, there was always that slightly irrational hope and denial of what’s going on and um [there’s] the horrible sense of loss when you come out of there knowing.”

(Sue, p.408)

For some women, denial prevailed even after medical confirmation, in hope the pregnancy was not over: *“It is not true that the foetus is not alive”* (Adolfsson et al., 2004, unknown, p.551).

In contrast, three studies ranging from mid-to-high quality, described the opposite process, whereby the mind is aware of miscarriage prior to the body (Carolan & Wright, 2017; Simmons et al., 2006; Andersson et al., 2012). Carolan and Wright (2017), articulated a belief that only once participants cognitively acknowledged the miscarriage, did the body expel the foetus. Which may suggest a protective mechanism whereby the mind can start to process the trauma before it fully unfolds:

“Almost every single time, before anything was scheduled for a D & C [dilation and curettage] or whatever. I would just miscarry on my own naturally. It was almost like I had to find out there was no heartbeat to let go. It’s so in our minds, we have such power over our bodies.”

(Carolan & Wright, 2017, Rachele, p. 147)

The other two studies described women’s heightened attunement and attendance to the absence of physical symptoms associated with a successful pregnancy, such as

nausea and tender breasts. This alerted them to miscarriage before there were any physical signs of loss or a miscarriage was medically confirmed (Simmons et al., 2006). Additionally, the presence of such symptoms provided reassurance in subsequent pregnancies (Andersson et al., 2012). All three studies included women with prior experience of miscarriage, which may indicate the development of a symbiotic relationship between the mind and body, following previous miscarriages.

Two studies which included women at similar stages of gestation at pregnancy loss (between 5 – 15 weeks), described how participants were emotionally ‘blocked’ by awaiting physical medical procedures (Gerber-Epstein et al., 2008; MacWilliams et al., 2016).

A participant detailed her struggle with feelings of “*ambivalence*” (Gerber-Epstein et al., 2008):

“The thought of carrying a dead embryo inside me drove me crazy...I was terribly confused on the one hand, take it out because its dead, and on the other: don’t touch, it’s my child...”

(Anatt, p.12)

However, although both studies reflected high-quality ratings, neither provided an account of the researcher's position, limiting the credibility of this finding.

Three studies provided evidence that the physical and accompanying visceral emotional experience of miscarriage triggered feelings of loss. Batool and Azam (2016), reported that for some women, the current experience of “*abdomen pain*” reminded them of the “*loss*” of their baby (Esha, p.640). Two additional studies explicitly commented on the ease with which the physical and subsequent emotional pain was recalled by participants (Gerber-Epstein et al., 2008; Adolfsson, 2010).

Unfortunately, the exact duration of this process cannot be fully determined, as Adolfsson's (2010) study failed to detail the length of time elapsed since miscarriage to interview.

1.3.2.2 Cognitive appraisals

With medical explanations provided for miscarriage being rare, women attempted to make sense of their experiences and establish meaning through cognitive appraisal.

Some women provided their own biological rationale for their loss (Simmons et al., 2006; Maker & Ogden, 2003). Others engaged in self-blame, with reasons such as previous abortions, not wanting the baby enough, working and lifestyle choices (e.g. smoking and drinking alcohol) cited by Adolfsson et al. (2004). Similar findings were presented by three additional studies (Maker & Ogden, 2003; Adolfsson, 2010; Simmons et al., 2006). Assuming personal responsibility for the miscarriage was associated with emotions of self-directed anger, shock, embarrassment and guilt (Adolfsson et al., 2004; Adolfsson, 2010).

Just one study detailed the process of women internalising attributions of blame posited by wider society, which led to lowered self-esteem and increased isolation (Batoool & Azam, 2016):

“...Elderly women direct me to keep a distance from young girls after miscarriage to save them from my projection...I am a bad omen for successfully expecting mothers...”

(Sana, p.642)

These findings may reflect a cultural subtlety in the experience of miscarriage, as the study was carried out in Pakistan which emphasises a collective culture.

A spiritual explanation for miscarriage was also sought by women (Hamama-Raz et al., 2010; Batool & Azam, 2016; Carolan & Wright, 2017; Ogden & Maker, 2003; Swanson et al., 2007). In studies that explicitly detailed religious faith, miscarriage was presented as “*punishment*” by women believing they had failed to meet religious expectations (Batool & Azam, 2016) or it provided a way for women to externalise their “*anger*” (Hamama-Raz, 2010).

In two studies, which did not detail the religious beliefs of participants, miscarriage was considered philosophically, with pregnancies being categorised as not being ‘right’ (Carolan & Wright, 2017) or the loss attributed to fate: “...*I don’t know if it was destiny, these things happen.*” (Maker & Ogden, 2003, Penny, p.410), which promoted acceptance. Each approach facilitated women to make sense of their loss.

Cognitive appraisals were also used to reframe the experience of miscarriage, by comparing their situations to others’ that were difficult, which improved self-esteem (Maker & Ogden, 2003):

“...*a lot of people have AIDS or cancer, they have worse things you know...so I think I am pretty lucky.*”

(Penny, p.409)

This strategy was described in a further study, as helping women to cope with the loss (Batool & Azam, 2016), which is further detailed in the subtheme, ‘*what remains*’.

1.3.2.3 Emotions: Active grief

Studies presented a range of difficult emotions that represented an ‘active grief’, which was a term introduced by Swanson et al. (2007); this is used within this theme to describe the current emotional processing of grief.

Women in five studies articulated they felt unprepared for miscarriage mentally, physically and emotionally (Carolan & Wright, 2017; Gerber-Epstein et al., 2008; Hamama-Raz et al., 2010; Ogden & Maker, 2003; Meany et al., 2017). As described by a participant in the Gerber-Epstein et al. (2008) study:

“You don’t expect it...but when it happens to you, boom! Total surprise. It simply hurts, hurts in the heart...real pain, physical pain.”

(Ruth, p.13)

The unexpected nature of miscarriage was found to trigger a range of emotions detailed across all studies including: shock, isolation, anger, frustration sadness, envy and as described in theme 2a, denial. This led to some women feeling overwhelmed:

“I feel very selfish. I feel very lonely. I cry almost every day. I feel very depressed. I feel overwhelmed. I feel desperate...I feel like I am going crazy.”

(Swanson et al., 2007, unnamed)

The emotional turbulence experienced in grief was also physically embodied. Participants in Adolfsson et al.’s (2004) study, described feeling:

“exhausted, feeble...I think I got very tired...the strength fell away.”

(unnamed, p.552)

Expanding on this, participants in Carolan and Wright's (2017) study conceptualised this feeling as "*depression*", describing their behavioural actions:

"I kind of went into depression...I felt like I was going through the motions of life...I'd be in bed by 6pm every night."

(Pamela, p.148)

The duration of time that women experienced the emotional turbulence appears to be unique to the individual. This is difficult to confidently determine, with most studies failing to reference specific time points in the presentation of their findings. Those that did provided a mixed account, with some women reporting difficult emotions subsiding after a few weeks (Ogden & Maker 2003; Gerber-Epstein et al., 2008) and others still feeling the emotional impact of the loss for years after the event (Gerber-Epstein et al., 2008; Adolfsson et al., 2004; Simmons et al., 2006).

Interestingly, Swanson et al. (2007) noted a qualitative difference in the nature of emotions between women grieving at 4 months, which was centred around "*sadness*" and those grieving at a year, which was associated with feelings of confusion, emptiness and disconnection.

In contrast, there is evidence to suggest that women whose pregnancies are unintentional, do not experience 'difficult' emotions related to active grief following miscarriage (Simmons et al., 2006; Maker and Ogden, 2003). A participant in Simmons et al's (2006) study explains:

"I had no feelings as such, I just took it in my stride...I was not sad or broody or upset in anyway..."

(Participant 4120, p. 1941)

Unfortunately, the extent to which this finding can be interpreted as being reflective of unplanned pregnancies is limited as the majority of studies included in the review failed to reference whether participants' pregnancies were desired.

1.3.2.4 Interpersonal connections

The way interpersonal connections were involved in adjusting to the miscarriage, was described by 12 studies.

With most participants presented as being in heterosexual relationships, this primarily focussed around their male partners, who were depicted as demonstrating a mixed response to miscarriage. Women described feeling lonely and isolated when their partners chose to deny the existence of the pregnancy (Maker & Ogden, 2003) or, acknowledged the significance of the loss but failed to understand the intensity of feelings experienced by the woman (Harvey et al., 2001; Gerber-Epstein et al., 2008; Hamama-Raz et al., 2010; Carolan & Wright, 2017). This is exemplified by a participant in Carolan & Wright's (2017) study:

“My husband admitted, he says it's different for me, 'I hate to say it, I don't feel it like you feel it, I don't understand'.”

(Joni, p.148)

Despite findings that suggest men did not have the same experiences of grief as women, three studies detailed how valuably they provided emotional support by acknowledging the women's loss and empathising with her experience (Maker & Ogden, 2003; Hamama-Raz et al., 2010; Batool & Azam, 2016).

Uniquely, Meaney et al. (2017) described how existing dependents helped to shape the experience of miscarriage by providing a distraction:

“I was upset for a good while after, but I had three other children to keep me going with school and everything...”

(Participant 10, p.5)

Benefit was found in sharing experiences of miscarriage with friends or family members who had experienced a pregnancy loss (Carolan & Wright, 2017; MacWilliams et al., 2016; Meaney et al., 2017; Maker & Ogden, 2003; Andersson et al., 2012). As a participant from Maker & Ogden (2003) explains:

“...I related that I had had a miscarriage and then she opened up and she said it was her third...you could relate to somebody, and I felt I was relating something and also sharing and helping...so it was helping each other.”

(Brenda, p. 410)

However, often the sense of disenfranchised grief was reinforced by friends and family, which encouraged feelings of isolation (Gerber-Epstein et al., 2008; MacWilliams et al., 2016; Harvey et al., 2001):

“I was really disconnected...Like family and friends didn’t really acknowledge it. It was almost like people treated it as a disappointment, like you didn’t get the job you wanted. I felt like it was ‘Oh, that’s too bad’.”

(Janet, p.508).

The connection with wider family context was important in shaping the experience of women in the Pakistan-based study (Batoool & Azam, 2016). An example is provided of a woman valuing: *“The support from her side [mother-in-law] more than the support from my mother”* (Sofia, p.642).

In-laws are described as having a “*special place*” in collective societies. Thus, the extent to which they are supportive of women during miscarriage may have a greater degree of influence, compared to other studies included in the review.

Women in three studies also established connections with the dead foetus, by engaging in behaviours that served to continue their bond and attachment, in the absence of official graves (MacWilliams et al., 2016; Adolfsson et al., 2004; Batool & Azam, 2016). This was achieved through direct handling of remains from the womb, with participants holding “*clots of blood/foetus*” while contemplating the lost baby (Adolfsson et al., 2004, p.553). Batool and Azam (2016) noted the development of associations with items intended for the baby: “...*I used [to] talk to the toys I brought for him...*” (Izza, p.641), which led to simultaneous feelings of gratification and pain.

1.3.2.5 What remains...

Following miscarriage, seven studies both explicitly and implicitly articulated outcomes for women which were primarily related to either personal growth or continued pain and uncertainty.

Four of the studies referenced women experiencing positive developments in the aftermath of miscarriage, which could begin as early as one-week post miscarriage (Swanson et al., 2007). Linked to the theme ‘*Interpersonal Connections*’, these were often associated with improvements in intimate relationships, with reports of increased closeness and unity (Hamama-Raz et al., 2010; Batool & Azam., 2016; Ogden & Maker, 2003; Swanson et al., 2007). Hamama-Raz et al. (2010) offers an explanation for how growth is cultivated from the pain in a couple:

“At first you do need to give space to bereavement and sadness, but in the end you can use it like other kinds of energy, as motivation to make things right again... like all pain, sometimes it clarifies things...if things aren't good [in the relationship], it can clarify emotions and can bring you even closer.”

(Woman, Couple 5, p.257)

It is important to note, in this sample participants were observing Jewish law (Hakakah) as part of their faith which prohibits physical affection between partners following miscarriage. This may have encouraged the couple to focus on improving the emotional aspects of the relationship.

Outside of their relationship's women experienced additional personal gains, which encouraged reflection on their lives and situation. Maker and Ogden's (2003) study demonstrates that this was true for women irrespective of whether the pregnancy was intentional or unintentional:

“I think I learnt quite a lot from it...it was like a kick up the bum...it was like don't waste your life...I'm sort of in some ways happier and stronger than I was before it happened.”

(Jenny, p.12)

Additionally, as detailed in the **theme** 'Cognitive Appraisals', personal strength was also achieved through considering their position in contrast to other women.

For some women, there was an absence of complete resolution. This was punctuated by future uncertainty related to their ability to bear children, which is outlined in theme 'Deconstruction in miscarriage'.

Lack of resolution was also characterised by avoidance. Three studies articulated women's desire to avoid future pregnancy for fear of the emotional and physical pain of miscarriage (Adolfsson, 2010; Harvey et al., 2001; Meaney et al., 2017). For Gerber- Epstein's (2008) participants, who referred to this period as living with chronic illness, it involved avoiding contact with other women who were pregnant, which highlighted their own loss:

"Her pregnancy was a living reminder of my loss, and as it advanced I could see what I was not."

(Malkah, p. 20)

Additionally, the unresolved pain and uncertainty sought outlet in subsequent pregnancies. This is highlighted by Andersson et al. (2012), who found pregnant women engaged in behaviours to reduce emotional distress and the potential for future miscarriage, as referenced in '*The mind-body connection*'. The behaviours included seeking reassurance by requesting ultrasound scans, being hypervigilant to their physical symptoms in addition to emotionally distancing themselves from the pregnancy:

"I don't feel right thinking of a child in my stomach as I may have felt before...I put some distance between myself and the pregnancy".

(unnamed, p. 266).

1.4 Discussion

The purpose of the current systematic review was to synthesise the qualitative literature related to women's experience of miscarriage, to provide an understanding of the psychosocial processes involved. The synthesis of 13 papers led to the

identification of two overarching themes, which summarise the main psychosocial processes involved in miscarriage as: '*Disrupted identities*' and '*Recovery*', each containing subthemes. Considered mutually, the themes provide an understanding of what is lost through miscarriage and subsequently the way women adjust to the loss.

1.4.1 Significance of main findings

The psychosocial processes involved in '*Disrupted identities*' are fundamental in understanding women's experience of miscarriage, emphasising how both in pregnancy and following gestational loss, women go through a series of rapid and intense changes. Importantly, women start to identify as mothers in relation to the developing child during pregnancy. This process parallels that of women who successfully give birth, whereby during pregnancy they start emotionally and cognitively incorporating the unborn child into their self-identities (Laney, Hall, Anderson, & Willingham, 2015; Smith, 1999). This is salient as both groups of women undergo the same internal preparations for motherhood, but those that miscarry have developed a new identity that cannot fulfil its purpose, as they do not have a child. Consequently, highlighting the sense of loss experienced in miscarriage is reflective of both an unrealised identity, in addition to the loss of an attachment to the unborn child, which has previously been hypothesised (Brier, 2008; Klier et al., 2002). In establishing the importance of the pregnancy pre-miscarriage, the synthesis extends existing knowledge summarised in reviews which have tended to focus on the post-miscarriage period (Brier, 2008; Klier et al., 2002; Lok & Neugebauer, 2007; Radford & Hughes, 2015).

'*Recovery*' presents the key psychosocial factors involved in women's adjustment to miscarriage. It incorporates concepts identified by previous reviews, such as grief,

anxiety and depression, combining them with a more comprehensive range of experiences in miscarriage, providing a broad framework for understanding the processes involved as women recover from miscarriage.

For example, the current synthesis identified the presence of emotions, such as shock, feeling unprepared and sadness which is consistent with the emotions depicted in grief in miscarriage (Brier, 2008; Lok & Neugebauer, 2007). However, this review suggests these experiences can persist for years following miscarriage and provides evidence that different emotions are experienced by women whose pregnancies are unintended. This extends knowledge from existing reviews which identify grief as being present for 6-12 months and provides variations in the emotional experience (Brier, 2008; Lok & Neugebauer, 2007). Interestingly, the current review confirms that women have cognitions relating to blame and self-judgment leading to emotional distress (Brier, 2008; Klier et al., 2002; Lok & Neugebauer, 2007). However, it additionally suggests that spirituality may mediate recovery by helping women to make sense of the experience, which Briers (2008) was previously unable to establish.

Mind-body dualism is identified in the synthesis as being crucial in recovery from miscarriage, with both working in tandem to allow the safe processing of miscarriage. Denial appears to be a key concept in protecting women both physically and emotionally from the immediate potential trauma of miscarriage. This complements previous research which acknowledged its role in avoiding physical trauma and in the processing of grief responses (Brier, 2008; Lee & Slade, 1999). This suggests medical and psychological interventions need to be mindful of the mind-body connection and work sensitively with women to ensure they do not

disrupt its protective function, which may contribute to unnecessary emotional distress.

The current review widens understanding of the complexity of interpersonal relationships in miscarriage. It extends findings from a previous qualitative review which concluded women with prior experience of miscarriage offer the best source of support (Radford & Hughes, 2015). It identifies that partners, friends and family, can also offer support if they are able to acknowledge the extent of the women's loss and emotional distress despite not having direct experience of miscarriage.

Additionally, it proposes that maintaining a relationship with the dead foetus, is another potential source of support available to women. This is consistent with the theory of continuing bonds, where maintaining contact with the deceased can be emotionally adaptive for bereaved people and help them to function despite their loss (Stroebe, Schut, & Boerner, 2010).

Following miscarriage, personal growth was identified, which is a novel finding in the context of the referenced reviews (Radford & Hughes, 2015; Briers, 2004; 2008; Lok & Neugebauer, 2007). This emphasises that some women experience life-enhancing developments following their loss. However, this concept requires further exploration, as the review failed to understand its wider impact. For example, it is unknown to what extent growth affects emotional and cognitive processes, such as increasing resilience and whether these changes offer protective benefits in subsequent pregnancies (Jayawickreme & Blackie, 2014).

Finally, it is of significance that the current review established there are cultural differences associated with the experience of miscarriage, pertaining to the social context and the influence of specific religious beliefs (Batoool & Azam, 2016;

Hamama-Raz et al., 2010) which may influence women's responses to the event. However, the generalisability of these findings is limited due to them being described by only two studies.

Therefore, considering the overall significance of the findings it is apparent that miscarriage is a complex phenomenon. Although the results do not provide a sequential model of psychosocial processes, they do provide a more nuanced presentation of the experiences than existing conceptualisations to-date.

1.4.2 Limitations with the included studies

Though there was a great degree of consistency apparent across the experiences detailed in the synthesis, there were also differences. However, as a consequence of the methodological limitations within the included studies, these must be considered cautiously and viewed as hypotheses requiring further exploration.

For example, the synthesis highlighted when demographics may have influenced the impact of miscarriage, which included factors such as current reproductive status, recurrent miscarriages, older age of gestation, week of pregnancy at loss and whether the pregnancy was planned. Unfortunately, it was impossible to establish the salience of each factor due to inconsistencies in the reporting of demographic factors in the methodologies of included studies, if they were included at all (see Table 1.3).

Furthermore, the majority of studies conflated participants' experiences in the findings by failing to present sufficient contextual information to evaluate individual contributions. Consequently, the current synthesis was unable to identify any meaningful patterns across the studies relating to these factors or draw overall conclusions, which is consistent with findings reported by reviews including

quantitative data (Brier, 2008; Geller et al., 2004; Klier et al., 2002; Lok & Neugebauer, 2007).

A further challenge was presented by the quality of the included studies. In keeping with the review's primary aim, all studies provided insight into participants' psychosocial experiences. However, while individual studies had specific limitations (Appendix E), two key areas of methodological weakness were identified across the body of literature, that are deemed important in determining the extent to which participants' accounts are accurately represented in the qualitative literature (Mays & Pope, 2000).

Firstly, there was restricted use of verification procedures. Although only two studies failed to use any verification strategies (Adolfsson, 2010; Maker & Ogden, 2003), the rest commonly relied on the use of just a single method, which usually entailed an additional coder or consultation with 'experts' to check coding and theme development. Unfortunately, multiple techniques were only described by one study, which additionally included respondent validation (MacWilliams et al., 2016).

Secondly, there was little use of researcher reflexivity, with just two studies acknowledging the researcher's position including how it may have influenced data collection and analysis (Carolan & Wright, 2017; Hamama-Raz et al., 2010) Both methodological flaws pose threats to the validity, reliability and credibility of the included research (Mays & Pope, 2000).

1.4.3 Limitations with the current review

Whilst efforts were made to ensure the systematic review was methodologically rigorous, there were limitations which do present a challenge to the quality of the review.

The scope of the findings may have been limited by the eligibility criteria. It is of note that the majority of studies included in the review are from Europe and North America, primarily reflecting a homogeneous socio-demographic. Studies from additional countries were excluded during the screening process due to the full-text not being accessible in the English language however, their inclusion may have broadened the evaluation of cultural diversity in miscarriage. Furthermore, the decision to exclude non-published literature meant that two doctoral theses were excluded. These may have provided alternative insights into the experience of miscarriage due to their utilisation of alternative designs, such as autoethnography (Sell-Smith, 2013) and unique methods of data collection, such as artwork (Mahone, 2015).

Moreover, the quality of the findings presented in review would have been enhanced by recruiting an additional researcher during data extraction and coding in the thematic synthesis, to address biases in the interpretation process by the reviewer (Booth et al., 2016; Thomas & Harden, 2008). This would have improved the review's credibility in its development of themes, beyond consultation with supervisors (Thomas & Harden, 2008).

1.4.4 Clinical implications

At a societal level, the increased acknowledgement of women's motherhood and loss is important. Hence, it is suggested that the RCN's (2015) guidance promoting the provision of a birth/death certificate and the opportunity for formal burial or cremation after miscarriage, is considered for incorporation at national policy level within the UK. This may encourage a cultural shift in societal perspectives by recognising miscarriage as a legitimate death and bereavement.

Additionally, there are a number of implications related to the current NICE guidance. Initially, NICE (2012) could consider extending focus from the first 13 weeks of gestational loss to include experiences to the end of the 23rd week, thereby ensuring that all women experiencing miscarriage have access to quality and appropriate support. At present NICE (2012), only recommend giving information about the physical impact of miscarriage. However, the current review acknowledges women feel both emotionally and physically unprepared, therefore it would be prudent for HCPs to advise women and their partners about the emotional experience of miscarriage to help them to understand the process; importantly highlighting the anniversary of the miscarriage as a period of time that may encourage new feelings of loss (Swanson et al., 2007). This could be approached during health consultations and supported by written literature. Finally, it is suggested that HCPs receive psycho-education to encourage a comprehensive awareness of the range psychosocial responses associated with miscarriage, to enable them to provide sensitive and emotional care, in line with the current guidance (NICE, 2012). This could be disseminated via information leaflets, training and best-practice guidance.

In the context of establishing the effectiveness of psychological interventions, it may be advantageous for therapists to measure a broader range of outcomes beyond anxiety, depression and grief in miscarriage (Huffman, Swanson, & Lynn, 2014). Given the uniqueness of women's experience in miscarriage, measuring levels of satisfaction with the intervention may be more meaningful and insightful (Vogus & McClelland, 2016).

1.4.5 Research implications

Considering the limitations of the existing review, future research could aim to establish the role of personal and socio-demographic factors in mediating the psychosocial impact of miscarriage. This could be achieved by the recruitment of homogenous samples of women (e.g. those whose pregnancies were unintended or those with recurrent miscarriages) or adopting a longitudinal design that monitors patterns over time (Coolican, 2017). This would facilitate the identification of individuals who may be at greater risk of experiencing psychological distress.

Furthermore, a natural extension of the current review would be to focus specifically on exploring cultural differences in the experience of miscarriage by including studies from a broader range of countries or focus on diverse cultural samples within the UK. This would help to establish the commonalities and differences in the experience, which would be useful for HCP's working in multi-cultural contexts.

1.5 Conclusion

The purpose of this review was to systematically review and synthesise the literature with the aim of exploring the psychosocial processes involved in women's experience of miscarriage. Overall, the synthesis provided a framework for understanding the psychosocial context of miscarriage, which emphasises the importance of pregnancy in understanding the loss experienced in miscarriage, and details the key factors involved in recovery both during and following the experience. Subtle nuances are found within the psychosocial processes, which future research should seek to clarify, as these are not fully understood and would assist with meeting the wider needs of women who experience miscarriage. There is a need for a cultural shift in wider society to acknowledge the significance of

miscarriage, which may be influenced by changes at policy-level, which may also influence NHS care.

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Chapter 2: Empirical Paper

The lived experience of women with primary tokophobia

Written in preparation for submission to the: *Journal of Reproductive and Infant Psychology* (see Appendix A for author guidelines)

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2.0 Abstract

Objective: The current study aimed to provide an in-depth understanding of the experiences of women with primary tokophobia in the United Kingdom.

Background: Tokophobia, a severe fear of childbirth, remains under-treated in the United Kingdom despite its significant physical and psychological consequences. Currently there is a paucity of knowledge relating to women's experiences of primary tokophobia.

Method: Seven women were recruited from the National Health Service and an online forum. Semi-structured interviews were analysed using interpretative phenomenological analysis.

Results: Following analysis, three superordinate themes were identified: *An “existential angst, existential dread, existential fear”*; *The construction and control of women: “If you didn’t have tokophobia to start with...”* and *“Drive to reclaim: A process of integration”*.

Conclusions: Primary tokophobia’s conceptualisation as an anxiety disorder is considered in the context of an interaction between internal and external experiences. Clinical implications and future research directions are discussed.

Keywords: fear of childbirth, transition, women, phenomenological

2.1 Introduction

2.1.1 Background

The term tokophobia was first introduced by Hofberg and Brockington (2000), to describe a severe anxiety that was characterised by a feeling of dread and desire to avoid childbirth. It is categorised into two sub-types: (1) Primary tokophobia; experienced by women pre-dating their first conception (nulliparous) and as more recently proposed, by women who become aware of their feelings of dread during the early stages of their first pregnancy (McKenzie-McHarg & Poote (2018) and (2) Secondary tokophobia; occurring in women following birth which could be conceptualised as a symptom of birth trauma or Post Traumatic Stress Disorder (PTSD).

Despite suggestions that the birth status of women is important in understanding childbirth fear (Rondung, Thomtén, & Sundin, 2016), tokophobia is often used interchangeably in the perinatal literature with concepts such as Fear of Childbirth and Childbirth Anxiety which do not differentiate between the parous¹ status of women (Richens, Lavender, & Smith, 2018; Wijma & Wijma, 2017). Consequently, empirical evidence relating to tokophobia subtypes is limited, particularly with regards to primary tokophobia, which the current research aims to address.

2.1.2 Clinical context

It is estimated that between 6.3 and 14.8 percent of European women in the antenatal and postnatal period respectively experience tokophobia (Nilsson et al., 2018). It is associated with increased numbers of abortions and sterilisations to avoid birth and

¹ Birth status

reduce anxiety; with its link to maternal requests for caesarean section (c-section) prompting the National Institute for Health and Care Excellence (NICE, 2011; 2014) to recommend that specialist support is offered to women with the condition (Klabbers, van Bakel, van den Heuvel, & Vingerhoets, 2016); National Collaborating Centre for Mental Health, [NCCMH], 2014). Yet, an audit revealed that fewer than half of the responding National Health Service (NHS) maternity units adhered to this guidance, implying that the condition is unidentified or is identified and left untreated in women (Richens, Hindley, & Lavender, 2015; NCCMH, 2014).

2.1.3 Implications and consequences of tokophobia

The lack of identification and treatment of tokophobia has considerable implications for women physically. Those pregnant with tokophobia are less likely to go into spontaneous delivery (Nieminen et al., 2017). Additionally, elevated levels of anxiety during birth lead to higher concentrations of hormones related to the fight or flight response being released (e.g. catecholamines) which increase the risk of labour duration and instrumental intervention (Geissbuehler & Eberhard, 2002; Johnson & Slade, 2003; Nieminen et al., 2017; Sydsjo et al., 2013).

Moreover, having tokophobia in labour increases women's negative perceptions of childbirth irrespective of medical complications (Nilsson, Lundgren, Karlström, & Hildingsson, 2012; Garthus-Niegel, von Soest, Vollrath, & Eberhard-Gran, 2013). Subsequently, this enhances vulnerability to PTSD in the postnatal period, which can disrupt the early bonding process between mother and child and lead to insecure attachments (Ayers, Eagle, & Waring, 2006; Onley, 2008). Interestingly, a Swedish study concluded that the medical and psychosocial consequences of tokophobia in the antenatal and postnatal period led to higher levels of healthcare utilisation and

associated costs (Nieminen et al., 2017). Considering the wide-reaching consequences of tokophobia, it is essential that knowledge about the condition is improved in order to improve outcomes for women and their families and to reduce potential costs to the NHS.

2.1.4 Causes of tokophobia

Unfortunately, existing knowledge about the causes of tokophobia is narrow in focus. Whilst research indicates that the development of tokophobia is both complex and multi-faceted (Rondung et al., 2016), its conceptualisation as an anxiety disorder has meant the fear of childbirth has been framed medically. This has meant that research has concentrated on establishing its aetiology from the perspective of identifying a 'cause' located in the individual (Fisher, Hauck, & Fenwick, 2006; Nilsson et al., 2018).

To date, understanding of the potential personal contributing factors to tokophobia includes having a previous psychiatric diagnosis (such as anxiety or depression), previous sexual or physical abuse and specific fears related to: the unknown, loss of control in labour and, potential injury to self and the baby (Klabbers et al., 2016; Lukasse et al., 2010; Sheen & Slade, 2017; Storksen Hege, Eberhard-Gran, Garthus-Niegel, & Eskild, 2012). Receiving significantly less research attention, social factors such as the intergenerational transmission of negative birth stories, partner dissatisfaction and low socioeconomic status have been highlighted as contributing factors (Klabbers et al., 2016). Moreover, individual studies have demonstrated the role of health organisations in maintaining tokophobia with factors including, an absence of continuity of care and lack of collaborative birth plans, being emphasised (Fisher et al., 2006; Lyberg & Severinsson, 2010). However despite a growing

awareness of the determinants of tokophobia, the psychosocial pathways leading to the acquisition of primary tokophobia, and to a lesser extent secondary tokophobia, remain relatively unestablished (Rondung et al., 2016).

2.1.5 Qualitative studies

Very few studies have sought to understand the causes and consequences of tokophobia from women's personal accounts. Nilsson and Lundgren (2009), adopting a phenomenological approach, with a sample of Swedish women with primary and secondary tokophobia, detailed how women perceived childbirth as an event that had to be undertaken alone, leading to feelings of isolation and loneliness. In their study, women reported tokophobia led to a lack of trust in themselves and others, consequently undermining their belief in their ability to give birth.

Similarly, Nilsson, Bondas and Lundgren (2010), focusing on previous birth experiences in women with secondary tokophobia, found that the experience was characterised by isolation and loneliness and reported that women felt anxious, out of control and disconnected from the labour process. Whilst these studies deepen the emotional, relational and social understanding of tokophobia, much of the current qualitative empirical evidence, with a few exceptions, have been generated from women in Scandinavian countries, where the socio-cultural experience differs from that in the United Kingdom (UK). With concern directed towards the NHS for the increasing medicalisation of pregnancy and childbirth, which has been linked to perceptions of emotionally disconnected and disempowered birth experiences, it is important to establish women's experiences of tokophobia in this context (Gray, White, & Russell, 2015; Parratt & Fahy, 2003).

2.1.6 Rationale

Given the significant consequences related to tokophobia and its medicalisation limiting wider exploration of the construction of the condition, it is imperative that research extends knowledge into women's lived experience to facilitate a more comprehensive understanding of its development. Importantly, research has conflated the experiences of women with primary and secondary tokophobia, with the latter being over-represented in research sampling (Nilsson & Lundgren, 2009; Nilsson et al., 2010; Rondung et al., 2016; Nilsson et al., 2012); thus, the extent to which current knowledge reflects primary tokophobia lacks clarity. Finally, the dearth of studies conducted in the UK leaves considerable gaps in understanding its presentation in women in Britain. In addressing these issues, the current research intends to promote a more holistic understanding of tokophobia in women that develops before the birth of the first child, which reflects experiences in the UK. This increased knowledge will contribute to improving support for women with the condition.

2.1.7 Aims

The primary aim of the research is to understand: What are the lived experiences of women who have experienced primary tokophobia?

2.2 Methods

2.2.1 Research design

Due to the researcher's constructivist epistemological position, in understanding knowledge and meaning as being socially constructed and therefore requiring interpretation, a qualitative research approach was adopted (Crotty, 1998).

Qualitative research encompasses a number of different theoretical approaches to

understanding the social and personal experiences of individuals (Smith, Flowers, & Larkin, 2009). This study adopted a phenomenological approach to provide a subjective understanding of women's lived experience of primary tokophobia.

2.2.1.1 Interpretive Phenomenological Analysis

Within this approach, the research utilised Interpretive Phenomenological Analysis (IPA), a method which places importance on the meaning and understanding participants give to their experience. It takes an idiographic focus to capture and reflect participants' experience and then through the researcher, seeks to offer an interpretation that is rooted in the material provided (Larkin & Thompson, 2011). IPA is a well-established method suited to understanding both personal and health-care related experiences, offering the opportunity to reflect the convergences and divergences among a group with a common experience (Biggerstaff & Thompson, 2008). Given the exploration of a relatively unknown concept, IPA was deemed more suitable than methods such as grounded theory, which aims to generate theory based on larger sample sizes (Glaser & Strauss, 2009).

2.2.2 Participants

Consistent with IPA methodology a small sample size of seven female participants were recruited to the study.

2.2.2.1 Inclusion/exclusion criteria

Participants were recruited based on the inclusion/exclusion criteria; full details are displayed in Table 2.1.

Table 2.1: Inclusion and exclusion criteria

Criteria	Detail
Inclusion criteria	<ul style="list-style-type: none"> i. Identify as having primary tokophobia as defined by current study ii. Nulliparous² , Primiparas³ or Multiparous⁴ – if birth took place < 5 years prior to study participation iii. Access to specialist NHS support for tokophobia if currently pregnant iv. If previous birth experience to have requested a planned c-section v. Eldest child < 5 years vi. Based in England vii. Previous birth experiences to have taken place in the UK viii. No disclosed attempts of suicide or self- harm 12 months prior to study participation
Exclusion criteria	<ul style="list-style-type: none"> i. Other types of tokophobia ii. Non-English speaking

In the absence of a consistently applied definition of primary tokophobia, it was operationalised as a severe fear of pregnancy or childbirth that precedes the birth of the first child. Severe fear was determined by the avoidance of childbirth and a belief that the concerns about childbirth were beyond those usually experienced by women. In women who had children, they must have requested to give birth by c-section delivery. Demographic information about the selected participants is detailed in Table 2.2. Pseudonyms are used to maintain participants confidentiality

² To have never given birth

³ To have given birth once

⁴ To have given birth more than once

Table 2.2: Participant characteristics

Name	Age	Ethnicity	Birth status	Age of children	Relationship status	Household income	Education level	Employment status	Mental health status⁵	Mental health support for tokophobia
Daisy	30	White British	Nulliparous (8 months pregnant)	--	Married	60,001 – 70,000	Postgraduate masters/equivalent	Part-time	Anxiety	Psychological therapy
Emily	42	White British	Multiparous	C 1: 2 years C 2: 3 weeks	Cohabiting	100,000 +	Postgraduate masters/equivalent	Full-time	--	Psychological therapy
Laura	32	White British	Primiparous	9.5 months	Married	50,001 – 60,000	Undergraduate degree/equivalent	Full-time	Anxiety	Psychological therapy & mental health nurse
Charlotte	30	White British	Nulliparous	--	Cohabiting	30,001 – 40,000	A-Level/ equivalent	Full-time	--	--
Hannah	32	White British	Nulliparous	--	Married	30,001- 40,000	GCSE/equivalent	Full-time	Depression	Psychological therapy
Scarlett	31	White British	Nulliparous	--	Married	30, 001 – 40,000	Undergraduate degree/equivalent	Full-time	--	--
Felicity	33	White British	Primiparous	2 years	Married	70,001 - 100,000	Postgraduate masters/equivalent	Full-time	--	Psychological therapy

Note: -- indicates question was not relevant for the participant

⁵ Self-reported mental health status

2.2.3 Procedures

2.2.3.1 Ethical procedures

Ethical approval for the research was granted by Coventry University on 23rd May 2017 (Appendix F) and by the Research Ethics Committee and Health Research Authority on 28th July 2017 (Appendix G). It was subsequently registered with the NHS Trust's Research and Development department (Appendix H). The research was designed to adhere to the ethical guidelines recommended by the British Psychological Society (BPS, 2014) pertaining to confidentiality, obtaining valid consent, minimising risk and debriefing participants.

2.2.3.2 Material

Measures

A 16-item screening measure (Appendix I) was used to establish participants' suitability against the inclusion and exclusion criteria. In the absence of a suitable brief screening measure for primary tokophobia, this included questions to ensure participants' experience of tokophobia met with the study's criteria, involving "yes", "no" or "unsure" responses. The screening questions were developed in consultation with the research literature relating to tokophobia; a supervisor with specialist expertise in tokophobia and academic supervisors.

Demographic information was gained from participants using the questionnaire in Appendix J.

Interview Schedule

In accordance with IPA guidance, a semi-structured interview schedule was developed (Smith et al., 2009). This enables both the researcher and participant to

mutually define the interview by providing guidance for the topic under review, facilitating participants to ‘give voice’ to their experiences and for the researcher to follow-up pertinent lines of inquiry (Opdenakker, 2006; Smith et al., 2009). The interview schedule consisted of five main open-ended questions supplemented by additional prompt questions (Appendix K). The researcher developed the interview questions via knowledge gained from observation of an online tokophobia forum, along with consultation from a supervisor with specialist expertise in tokophobia and academic supervisors.

2.2.3.3 Recruitment procedures

A purposive sampling method was used to facilitate homogeneity and in acknowledgment that women with primary tokophobia are a minority and potentially hidden group (Silverman, 2013; Smith et al., 2009). Additionally, women were recruited from two sources to ensure sufficient numbers of participants could be accessed (Ellard-Gray, Jeffrey, Choubak, & Crann, 2015).

A poster (Appendix L) was placed in an online support forum; 10 people registered their interest by either posting a response or sending an email. Further recruitment was conducted through an NHS Trust. Patients who had been treated for primary tokophobia were sent an invitation letter (Appendix M), a poster was also placed in a waiting room. Seven participants responded to the letter and poster with a request for further information.

All 17 respondents were emailed a copy of the information sheet (Appendix N) and a copy of the consent form (Appendix O) with instruction to contact the researcher if they remained interested and had any questions about participation; four respondents failed to make further contact. The remaining respondents returned their consent

forms and received a telephone call to complete the screening process. This phase led to the exclusion of four participants due to failure to meet the study's inclusion criteria; two resided outside the UK and two did not meet the study's definition of primary tokophobia. Two further participants were unavailable within the research period, therefore seven participants accepted interview dates. The General Practitioners of women who were pregnant or recruited through the NHS were informed of their participation (Appendix P). Participants' locations included the: West-Midlands ($n=4$), South-West ($n=1$), North-East ($n=2$).

2.2.3.4 Interview procedures

Interviews were conducted between 25th August 2017 and 15th December 2017. Six were conducted in participants' homes and one in a hospital interview room.

Interviews were audio recorded and ranged in duration from 52 minutes to 124 minutes ($M = 93$ minutes).

Prior to interview commencement, details from the information sheet and the consent form were revisited. Participants were given an opportunity to ask questions and agreement to participate was re-established. Subsequently, they completed the demographic questionnaire (Appendix J).

Following the interview, the researcher verbally went through the debrief sheet, of which participants were provided with a copy (Appendix Q), and time was provided for questions.

2.2.4 Analysis

As recommended by Smith et al. (2009), audio recorded data was transcribed verbatim with identifiable information being replaced by pseudonyms or omitted.

Data was analysed in accordance with Smith et al. (2009) procedures for IPA, which are detailed in Appendix R. To provide an overview of the analysis process excerpts of coded transcripts are displayed in Appendix S, with a visual representation of the process of theme development provided in Appendix T.

2.2.4.1 Validity and credibility

Following Yardley's (2000) recommendations, validity and credibility were assessed. Data verification was completed with a member of the wider research team to assess emergent codes and themes. Superordinate and subordinate themes alongside examples of linguistic, content and analytical coding were additionally shared. Finally, credibility of the findings was established through respondent validation, an excerpt of which is in Appendix U.

2.2.4.2 Reflexivity/Researchers position

In acknowledgement of the researcher as an inherent part of the research process, reflexivity is recommended in understanding one's emic and etic position (Berger, 2013; Greene, 2014). Thus, my experiences as an: educated female of dual heritage who occupies the position of a mother with experience of instrumental-assistance in labour, in addition to being a politically conscious NHS employee, will ultimately influence my position in data collection and analysis. Thus, in an attempt to provide insight into the material and transcend my position, a bracketing interview was completed prior to interview commencement (Finlay, 2008). Additionally, a reflective research diary was maintained throughout the research process.

2.3 Results

Following data analysis, three superordinate themes emerged: *An “existential angst, existential dread, existential fear”*, *The construction and control of women: “if you didn’t have tokophobia before...”* and *Drive to reclaim: A process of integration*. Each superordinate theme contains two subordinate themes, these are displayed in Table 2.3. Throughout the results, the divergence and convergence of participants’ narratives are illustrated.

Table 2.3: Superordinate and subordinate themes

Superordinate theme	Subordinate theme
An “existential angst, existential dread, existential fear”	Death in the frame The transforming self
The social construction and control of women “If you didn’t have tokophobia before...”	Society: “A bad woman” The medical context
Drive to reclaim: A process of integration	Disconnection Connecting: Through time, space and language

2.3.1 Theme 1: An “existential angst, existential dread, existential fear”

All participants' experiences encompassed existential elements. Childbirth reflected a symbol of change in participants' lives, for both those who were contemplating motherhood and those who had experienced pregnancy. It altered participants' self-perceptions and led to adjustments in previously established notions of responsibility

and life meaning. These were explored through the sub-themes: *Death in the frame* and *The transforming self*.

2.3.1.1 Death in the frame

All participants reflected on the physicality of childbirth, with it being construed as a: “*terrifying*”, “*horrific*”, “*traumatic*” and a “*violent process*”, Daisy detailed how vaginas, “*stretch and tear*” and Emily portrayed how bodies are, “... *essentially being ripped apart from the insides*”. Their evocative use of adjectives and graphic choice of verbs indicated the powerful threat vaginal birth posed to the participants’ sense of their physical self. This contributed to a doubt that their bodies would withstand childbirth as detailed by Felicity, “*what if I can’t manage the pain*” resulting in a fear of the event.

The threat to the physical self was compounded by all participants’ awareness of the relationship between childbirth and mortality gained through proximity to foetal death or personal and maternal mortality when they were born.

Charlotte, who was born prematurely spoke of her mother’s mortality becoming ingrained in her childhood narrative:

“She nearly died giving birth to me, so I was there months early, so I’ve heard that story like so many times.”

(Charlotte, lines 183-184)

Two further participants reflected on their own mortality during birth:

“I was born at 26 weeks, I weighed 1 pound 7 ounces 31 years ago, so it does kind of interest me how medical advances you know, there are babies that can be born 1 pound 1 ounce that you know 30 years ago [pause].... I mean I’m surprised I survived to be fair.”

(Hannah, lines 296 – 297)

“... when you go through labour you tear up and then oh, you know, you can die... you know how am I meant to push when all these other things are telling you not to push...”

(Daisy, lines 460 – 462)

The contemplation of fragility and “*survival*” demonstrated an acute awareness that there was a potential for death and suggested a felt burden of responsibility for the preservation of life.

Hannah, who had not been pregnant, highlighted pregnancy as a “*ticking-time bomb*”:

“I wouldn’t be able to see past that due date, to me, that would be like that this is the day I am going to die, because that is what it feels like for me, I wouldn’t be able to see past it at all.”

(Hannah, lines 130 – 132)

The proximity of death in childbirth and Hannah’s assertion of not being able to “*see past it*”, possibly indicated a fear of death relating to both the physical and internal self, compounded by not knowing what form of self would emerge post-birth. This sentiment was echoed by Laura who reflected on her fear as “*blocking*” her ability to

visualise motherhood. Similar experiences were reported by Felicity, Scarlett and Emily.

2.3.1.2 The transforming self

Linked to the concept of an internal death, all participants discussed how their tokophobia was characterised by the ‘self’ evolving.

Emily’s pregnancy experience was punctuated “*with one fear being replaced by another*”. She conceptualised the process of having a baby as an: “*existential angst, existential dread, existential fear*”. For her, the use of “*existential*” appeared to symbolise the disruption to the sense of purpose she had established in life; this began pre-conception and continued through to the post-natal period where she had got her “*head round the responsibility of having a child*”.

Similarly, Felicity described the way changes in her physicality during pregnancy caused her distress:

“I got absolutely massive...I'll never get back into those clothes. I've lost who I am a little bit, I kept reminding myself, well actually this what happens, and it will work itself out and everything else. I didn't like having a bump...it was the first thing that I was proud to get rid of, now I can be a Mum, that's what I wanted.”

(Felicity, lines 379-385)

Felicity’s self-identity was strongly linked to the body she was familiar with pre-birth. The present tense of “*I’ve lost*”, suggests an acknowledgement that part of her had gone that cannot be restored. Following the birth, she became reacquainted with

her former body image, which helped her to reconnect with the desire for motherhood and thus re-established her meaning and purpose.

Additionally, all participants described how their experience of tokophobia led to powerful changes in their interpersonal relationships.

Scarlett shared her “*guilt*” at having redefined the expectations of her marriage as a childless couple and she had reevaluated how her husband might have perceived and related to her:

“I was convinced he was either going to leave me or he was going to stay because he pitied me and didn’t want to upset me, and I thought he should leave me and find someone that did want to have children... now we’ve been together for long enough I think we both know where each other stand on it.”

(Scarlett, lines 547-555)

Additionally, Scarlett, Charlotte, and Hannah who felt unable to conceive described mourning the loss of the life they envisaged they would have:

“It hurts, it hurts that I won’t be a mum, it really does hurt, and it does put me into a depressive state...”

(Hannah, line 217)

Hannah’s experience emphasised the intensity of grief she felt at the loss of motherhood, indicated by the repetition of the word “*hurt*”. This led her to a “*depressive state*” which could be construed as lifelessness; she existed with a lost purpose, “*I literally go work, come home and go to bed*”. Thus, in comparison to the women transformed into mothers following pregnancy, the transformation of self in those who had not become mothers was typified by regret and sadness.

Hannah later reflected on her attempt to establish new meaning in life. She focussed on material items, however this maintained her on-going battle to find purpose as she was unable to replace the life she had imagined she would have:

“A couple of years ago I got a new car and I were like you know, you can screw having your babies I’ll have my car thanks very much erm, you know then it wore off a bit and then it comes back again...you are constantly fighting it.”

(Hannah, lines 218 - 220)

2.3.2 Theme 2: The construction and control of women: “If you didn’t have tokophobia to start with...”

In contrast to the internal focus in ‘*An existential angst, existential dread, existential fear*’, the way participants were externally perceived and treated moulded their experience of fearing childbirth in the current theme. An interplay of expectation, and stigma based on perceptions of femininity, served to dictate the experiences of participants; this promoted psychological distress and disempowerment. This was apparent at a societal level and the values appeared to filter into the microcosm of the medical context. The NHS was presented as an organisation of contrasts that adopted behaviours and attitudes which served to seize autonomy from women whilst simultaneously providing support. These experiences were reflected in the sub-themes: *Society: “A bad woman”* and *The medical context*.

2.3.2.1 Society: “A bad woman”

Friends and family perpetuated an assumption that childbirth was an ability intrinsic to women through the dismissal of participants’ fears of the event, with judgements

such as: *“it’s painful but it is what it is”* mentioned to Charlotte or *“ah just get pregnant and you’ll be fine”*, proposed to Hannah.

Scarlett explained the impact these attitudes had on her sense of self:

“I was failing as a woman to do what should be natural and everyone else said was a natural thing.”

(Scarlett, lines 733- 734).

Scarlett’s sense of *“failing”* to do something *“natural”* was suggestive of her internalisation of society’s view of gender essentialism, the idea that the biology determines the behaviour, and she subsequently felt shame for not reaching these expectations. This led to her feeling less than a woman; a concept that was woven into all participants’ narratives.

Conversely, each of the participants who had conceived presented an alternative to the discourse, such as that articulated by Daisy: *“I don’t think having stitches in your vagina is natural”*. This reflected both increased knowledge and an ability to define their femininity following pregnancy.

The feminine ideal was also evident in the stigma surrounding c-section with the phrase *“you’re too posh to push”* being presented to three of the participants and through the proliferation of *“negative”* birth stories told by friends, family and the media. This discourse culminated in a shared perception by the participants, that suffering is a rite of passage for women in childbirth:

“I think if men had to go through childbirth there’d be so much more work done about pain relief and lovely things that could be done to make you feel better, so it’s one of those ...it’s a woman’s thing...”

(Daisy, lines 127-128)

Daisy's account highlighted a perceived lack of parity between men and women, with a suggestion that as "*a woman's thing*" there is a societal belief that it is suitable for women, but not men, to endure pain and suffering.

A further experience conveyed by participants was society's ownership over their bodies. Laura voiced this through her experience of "*intrusion*" in pregnancy:

"I had an anger, I felt angry constantly, really angry, erm because, I found it so intrusive if somebody would ask me "oh are you planning to breastfeed" or you know "are your boobs feeling sore" I wanted to hit people...the hugest thing for me was the body thing, the changing, my changing body. I couldn't stand the fact that everybody knows how your body changes in pregnancy... I hated being in my own body..."

(Laura, lines 77- 87)

Laura, who described being traumatised through indirect familial sexual abuse, denoted a sense of feeling boundary-less through society's general knowledge of pregnancy. Her correction from "*the changing*" to "*my changing body*", reflected her struggle to retain ownership of her body from which she felt increasingly alienated. Her reiteration of "*anger*" emphasised the repeated violation she felt.

2.3.2.2 The medical context

Six of the participants reported having "*traumatic*" experiences previously in the NHS, these were in the context of vaginal examinations, injections, or premature birth (as outlined in '*Death in the frame*'). Subsequently, for these participants the physicality of childbirth, with its accompanying routine medical procedures,

presented the possibility of replicating the previous trauma and them reliving the feeling of intrusion.

Hannah explained:

"It's the pain, it's the medical invasive procedures it's, errr, the whole medical intervention, its drugs, it's the whole package for me."

(Hannah, lines 31-32)

Daisy described how “*frightening*” the prospect of vaginal examination in pregnancy was:

“[it’s]...completely disempowering and making you vulnerable and having strangers look at a part of your body that you probably keep very private the damage that could do is vast”. She suggests rather than “look” or “maybe have a feel”, it wouldn’t be “difficult” for medical staff to “introduce” themselves “so that women feel like they are part of something that is happening to them, you know.”

(Daisy, lines 334-341)

Daisy outlined how medical professionals engaged in the non-consensual examination of women’s bodies, reflecting a disconnection between the medical objectives of examination during pregnancy and health professionals’ attunement to the “*autonomy*” of the women in front of them. This served to alienate women from their body by subjecting them to invasion. Her adoption of casual language “*maybe have a feel*” reflected the lack of consideration ascribed to women's bodies. As a sexual abuse trauma “*survivor*”, this had the potential for retraumatisation.

As a consequence of “*tortuous*” experiences in healthcare, participants felt they were not “*listened to*”. This perpetuated a cycle of “*mistrust*” of NHS staff and reflected a misbalance of power; as the women were reliant on healthcare staff as they were “*responsible for making decisions*” about their care.

All the participants described inconsistent experiences of care in the NHS. One way this was described was through its approach to vaginal birth. Daisy, Emily, and Felicity identified aspects of their experience being dominated by the intense promotion of vaginal birth, constructed as “*natural birth*”, by healthcare staff.

For Felicity, despite having a c-section planned she experienced pressure to conform to a vaginal birth just before labour, by a consultant who suggested:

“...right you’re 11 days over...all we would have to do is give you a tiny bit of something and you’d be induced ...again I was very worried, then my anxiety went back up.”

(Felicity, lines 144-146)

Emily experienced her therapy as a process to convince her to have a vaginal birth comparing the process to: “*having abortion counselling from a pro-life organisation*”. She reflects on the impact this had, on her “*negotiating*” her c-section. She likened it to a trip to “*Dignitas*” for euthanasia:

“...I had been forced into a corner that perhaps that I might not have...a lot of people might be facing some inevitable shitty horrible death and saying I want to choose the way that I do this...they travel to Switzerland while they’re still healthy enough to do that because they can’t get the support they need or that they want at home so they maybe bail out earlier... I suppose on

one level I felt that I'd done something analogous to that."

(Emily, lines 378 – 384)

The account highlighted that Emily felt compelled to commit to a c-section while she felt “*healthy*” enough to assert her needs, due to the “*natural birth*” stance being adopted by her therapist in sessions, despite being uncertain if this was truly her desired birth outcome. Her comparison to “*Dignitas*” may have been, as outlined in theme 1a, related to the death of the ‘idealised’ birth and her sense of self, typifying the existential battle that characterised Emily's experience.

However, the promotion of natural birth was not consistent through-out women’s contact with health professionals. Laura reported how her:

“Mental health midwife and my consultant.... at no point actually did they try and convince me to go for erm, a natural birth.”

(Laura, lines 210-211)

Furthermore, three participants described experiences where they had received “*red-carpet*” treatment during their scheduled c-section, with their needs being prioritised. This was irrespective of all of three participants additionally having experienced pressure to give birth vaginally.

2.3.3 Theme 3: Drive to reclaim: A process of integration

Participants described attempts to regain control of their bodies and sense of self. They moved towards establishing a sense of cohesion to navigate the internal conflicts and changes established in ‘*An existential angst, existential dread, existential fear*’ addition to making sense of and surviving the social experiences described in ‘*The construction and control of women: “If you didn’t have*

tokophobia to start with...''. A nuanced range of strategies were utilised, which are detailed in the sub-themes: *Disconnection* and *Connecting: Through time, space and language*, reflecting two polarised but complementary approaches.

2.3.3.1 Disconnection

All participants described both unconsciously and consciously coping with their tokophobia using strategies that involved disconnecting with aspects of their experience. A fragmented narrative of their experience was offered by the three nulliparous participants, epitomised by multiple conflicting perspectives throughout their accounts.

Charlotte, at the point of the interview, had recently made the decision not to have children. This seemed to remove the anxiety perpetuated by the responsibility of making a choice, regarding whether to have children in the context of her tokophobia, by reducing uncertainty.

"It would just pop into your head like, do I want a baby? Don't I want a baby? It kind of drives you mad just thinking about it all the time... But now we're 100 percent we won't have children it's easier."

(Charlotte, lines 50-52)

Six of the participants described engaging in physical avoidance of personal triggers for their anxiety from pre-conception through to childbirth; this included friends, family, and media sources. Scarlett explained this in relation to her efforts to evade witnessing childbirth:

"It's a bit gross, something I might probably avoid" and continues *"Yeah [seeing it] might put you off having kids for life."*

(Scarlett, line 215)

Scarlett's avoidance appeared to serve a dual function: to control her viewing of distressing images and the preservation of her ability to have children by not being "put off". The regressive adolescent use of terminology "gross" potentially signified a juvenile conceptualisation of childbirth, keeping her 'childlike' and unprepared for embarking on adult transitional changes such as childbirth.

Laura, Felicity, and Emily described their utilisation of cognitive avoidance throughout pregnancy. Laura articulated her minimisation of the impact of tokophobia pre-conception, despite an awareness of being "uncomfortable" with pregnancy: *"when it's me it will be different"*. She reflected:

"There is part of me - I always assumed for some reason that I would have a problem getting pregnant."

(Laura, line 66)

Laura was able to become pregnant by believing she could not conceive, which implied she suppressed the other "part" of her that believed she could conceive. This coping strategy may have protected her desire to become a mother, resonating with Scarlett's account above.

For Felicity, cognitive avoidance manifested during pregnancy in response to the physical embodiment of anxiety: *"I'll ignore it, I'll ignore it, I'll ignore it"*. This suggests that if she ignored the signal of distress, the underlying problem may go away.

Conversely, Daisy's experience was not characterised by avoidance. This may be attributed to her feeling "*a lot safer*" as she sought pre-conception advice due to a cohesive understanding of the trauma origins of her tokophobia having spoken to professionals about it "*again and again*", which served to minimise her anxiety.

2.3.3.2 Connecting: Through time, space and language

Each of the participants detailed how establishing connections with others, themselves and their experiences helped them move through their individual journeys with tokophobia.

All participants' accounts illustrated how connecting with others helped them adjust to their tokophobia. Hannah described her experiences of acceptance, validation and allowing her true self to be seen, in a tokophobia forum:

"It's really good, to just be able to like vent and tell people how you feel and they aren't gonna go " oh just get pregnant it will be alright" they go "oh I know how you're feeling... this is how I got through it"...you can be yourself you can talk freely."

(Hannah, lines 362-367)

For Daisy, it was establishing plans for her care alongside health professionals:

"There's a flow chart which is good and although I'm not necessarily in control of the flowchart I know what will happen and why it's happening."

(Daisy, lines 640-641)

Daisy's experience demonstrated that by being included in decisions about her care, she gained knowledge and an ability to consent to the process. This led to a comfortableness in relinquishing full "*control*".

In all participants who been through pregnancy, time alone with the baby was important. This is illustrated by Laura who detailed:

“When I took myself out of work and spent some time walking and being on my own; I found that a little easier because then I almost felt like we were a bit of a team then, you know it was like, we will get through this...I felt like I started to bond a little bit more.”

(Laura, line 320-323)

In having space and time, she was able to notice her feelings and start to connect with her baby. Laura’s use of the word “*team*” potentially symbolised an internal cohesion which reflected a move from the baby being viewed as a threat to the self, as conceptualised in ‘*An existential angst, existential dread, existential fear*’, to an ally.

Equally the post-natal period provided time and space for women to connect with their experiences during pregnancy. This was important as all participants suffered postnatal distress. Emily described her experience of this:

“[After the first birth] I had this freedom to really work through even stuff that seemed crazy ... I was able to articulate to my community midwife that part of the issue had been it [the c-section] seemed a bit sanitised and I’d been given this baby without having done anything to earn her.”

(Emily, lines 917 -918)

With distance from the event, Emily was able to process and develop a cohesive understanding of her experience, including a deeper sense of the “*moral and*

philosophical” adjuncts to the process. Her reference to “*freedom*” might relate to her being re-connected with her autonomy, which had been hijacked in her first pregnancy.

A major element in some participants’ ability to connect others to their experience was through the development of a language and framework to discuss their tokophobia. Hannah used a metaphor:

“...it's like someone who is scared of spiders being locked in a room of spiders and being told on this date we are going to fill this room with them, it's the only way that I can- that I can explain to my husband that somebody can understand... It's like deep-rooted...”

(Hannah, lines 9-12)

The comparison to a spider phobia highlighted the primitive innate nature of her fear, whilst providing others with a powerful visual image which had the potential to invoke a strong visceral response and enabled them to empathise with her terror.

Whereas Emily, found religion provided her with the framework to understand and subsequently connect her with feelings and experiences she had not encountered before:

“I had a lot of religious metaphors....and this doesn’t make sense at all because I’m not, I didn’t have a framework for dealing with it because I’m not religious I don’t go to church, I didn’t have like a minister that I could talk to about it.”

(Emily, lines 387-389)

Emily utilised religious language and concepts, despite having declared herself secular, which might signal a lack of modern framework or language to describe the existential experiences.

2.4 Discussion

2.4.1 Summary of main findings

The study revealed the lived experience of primary tokophobia with representation from women in the UK, in pre-conception, pregnancy and post-birth stages. It draws together commonalities in women's narratives while highlighting divergences, which reflect the uniqueness and complexity of experiences that sit under the term tokophobia. Overall, the findings suggest a dichotomy between internal existential processes taking place in the context of societal demands and expectations, with women utilising their personal and social resources to manage the conflict. In considering the three superordinate themes together, the research suggests that primary tokophobia develops and is maintained, due to bio-psycho-social-spiritual factors that are unique to the individual, as opposed to a 'pathology' located in women (Prinds, Hvidt, Mogensen, & Buus, 2014; Walsh, 2002). This represents both a challenge and a contribution to the empirical evidence base which has largely presented tokophobia from a medical perspective, as an anxiety disorder. The superordinate themes will be individually reviewed in consideration of the wider literature.

2.4.1.1 Theme 1: An “existential angst, existential dread, existential fear”

Tokophobia was presented as embodying a period of transition, which was initiated by an awareness of the fragility of the self. Many of the concerns discussed within this theme, related to the content of women's fears and the loss of identity, are

consistent with previous findings (Sheen & Slade, 2017; Nilsson & Lundgren, 2009).

It broadens existing knowledge by drawing parallels with the features of an existential experience, which describe an individual's ability to meet the challenges posed by life (van Deurzen & Adams, 2016). Key existential challenges include: living fully despite the prospect of death and perceiving the vulnerability and weakness of the self to enable access to personal responsibility, strength and meaning (Adams, 2014). These propositions resonate with the participants' accounts of self-transformation through the perception of physical vulnerability and death of the self, which encourages contemplation and changes in responsibility, loss, grief, relational changes and establishing personal meaning.

Whilst existential concepts have not been widely discussed in the empirical literature pertaining to tokophobia, they have been extensively identified in several related areas, such as women's transition to motherhood, miscarriage and infertility (Boz & Okumus, 2017; Nikčević & Nicolaides, 2014; Prinds et al., 2014). The commonalities between the aforementioned experiences and tokophobia are noteworthy and suggest that tokophobia reflects a period of emotional distress and internal conflict in response to a life-transition. In this instance, it is motherhood, with childbirth reflecting a 'block' or 'gateway' to achieving this status. This is consistent with Erikson's (1963) theory of psychosocial development which proposes that conflicts must be experienced and resolved to progress onto the next developmental life stage (Onley, 2008). As such, the anxiety response in primary tokophobia should be considered not as a pathology but on the spectrum of reactions to a life transition.

2.4.1.2 Theme 2: The construction and control of women: “if you didn’t have tokophobia before...”

This theme addressed the contexts women live in which determine the development and maintenance of tokophobia.

The societal influences detailed throughout this theme are consistent with those previously identified as moderators of fear of childbirth (Hofberg & Ward, 2003; Luce et al., 2016; Rondung et al., 2016; Sheen & Slade, 2017). The current research indicates that women are subjected to complex and contrasting messages about femininity. Participants internalised an essentialist belief, that childbirth is ‘natural’ while simultaneously finding that medicine dominated their experiences; which can undermine a woman’s perceptions of her capabilities to give birth (Jolly, 2018; Nilsson & Lundgren, 2009; Parratt & Fahy, 2003). Rather than reflecting the reality of childbirth, which often involves physiological processes and medical intervention, society presents these two experiences as separate and distinct (Sweetman, 2017). Subsequently, women are unaware of the nuances of the female experience in childbirth, which may account for part of the psychological distress and disenfranchisement experienced in primary tokophobia. This indicates that the promotion of a more balanced and integrated perspective of childbirth may be required to limit the development and impact of primary tokophobia (Sweetman, 2017).

2.4.1.3 Theme 3: The drive to reclaim: A process of integration

Participants coped with primary tokophobia by disconnecting from the sources of their anxiety, enabling them to connect with their desires, themselves, others and motherhood, reflecting a process of cohesion.

Consistent with previous findings participants engaged in physical and cognitive avoidance for triggers of their fears (Hofberg & Brockington, 2000; Nilsson & Lundgren, 2009; Hildingsson, Nilsson, Karlström, & Lungren, 2011; Rondung et al., 2016). Uniquely, this study highlights that this removed the stimuli and reduced anxiety, while also preserving women's ability to conceive and subsequently give birth. Therefore, contrary to traditional constructions of avoidance reinforcing unhelpful behaviours, as with operant conditioning, in this context it appears to have an adaptive function (Hofmann & Hay, 2018), in helping women achieve desired motherhood. However, with all of the participants experiencing postnatal distress, it could be that avoidance was a contributing factor as it has been associated with postnatal depression (Razurel, Kaiser, Sellenet, & Epiney, 2013).

This study confirmed that establishing relationships with attuned professionals and wider social networks are important for women in coping with tokophobia (Fisher et al., 2006; Nilsson et al., 2010). Having time and space during the perinatal period to connect with themselves, their foetus and children, in addition to having the 'words' to communicate their distress, were key factors in helping women process their experience of primary tokophobia.

Taken together these findings propose a complex picture in helping support women with tokophobia; women may require avoidance to conceive and maintain pregnancy, but then additionally require time and space to allow for the emotional and cognitive processing of tokophobia both during pregnancy and in the postnatal period. This suggests that different strategies may be required at various stages during the perinatal period.

2.4.2 Societal, clinical and services implications

While the findings of the current study must be considered in the context of a small sample size, it does still provide a number of considerations. Overall, the findings suggest that it would be useful for society to consider some the current narratives around femininity and the impact these may have on the experiences of women and the development of tokophobia. Developing a shared language may contribute to a society that is open to the uniqueness of women's wishes and experiences relating to the decision to have children, pregnancy, childbirth and motherhood. This would help reduce women's experiences of disenfranchisement and may have a positive impact on tokophobia.

Clinically, there are several implications that arose from the research. Primarily, it would be helpful for NHS professionals involved in women's care to have a wider understanding of tokophobia, acknowledging that for some women it is part of their transition to motherhood, which presents as anxiety. There is the potential for this cultural shift to be influenced by the dissemination of the current findings via training, conferences and teaching.

Furthermore, services could explore ways to create protected time and space for women to consider their thoughts and feelings in response to this transition, which would also increase communication. This could be implemented by adjusting the NICE (2014) recommended screening practices for perinatal mental health difficulties, which currently focus on specific questions related to anxiety and depression. Based on the current findings this may not be effective in identifying primary tokophobia. Asking the question: 'How are you feeling about pregnancy?', in consultations with women who disclose they are either considering pregnancy or

are pregnant, may provide more opportunity for women to articulate their fear of childbirth. Additionally, informal space such as women's groups could be introduced by the NHS or third-sector organisations, that enable women from pre-conception through to the postnatal period to share their experiences. This may reflect a shift in the knowledge that is shared about childbirth, as the discourse will be generated by women. Both interventions may help with the promotion of tokophobia as a transitional process, by ensuring women with this experience are included.

Finally, it is acknowledged that some women may benefit from formal psychological support. The present findings suggest that psychological formulation would be useful in helping women develop a cohesive understanding of their experiences (Johnstone & Dallos, 2014). Additionally, whilst a range of therapies may be effective, the findings indicate that a narrative therapy approach may be worth exploring. It focusses on helping people to make sense of, and 'reauthor' their difficulties; placing them in an expert position while viewing their problems as separate to them and occurring because of their social contexts (Morgan, 2000).

2.4.3 Methodological limitations

The current research should be considered within the context of its limitations. It is acknowledged due to a small sample size the findings are not generalisable to all women with tokophobia. Related to this, the current sample does not reflect a significantly diverse socio-demographic group, with recruited participants identifying as having: a shared ethnicity and sexuality, in addition to similar levels of education and employment, with the majority having accessed mental health support for their primary tokophobia. Consequently, the extent to which tokophobia is

experienced by marginalised groups in the UK is unknown. This is important to establish considering the role of socio-demographic factors in the persistence of health inequalities (Marmot et al., 2010).

Further limitations are presented by the study's eligibility criteria which may have excluded individuals who could have made a valuable contribution to the research. Firstly, the criteria requiring participants to identify their fear as 'beyond ordinary fears' may have been problematic given participants only frame of reference is their experience, making this hard to identify. Secondly, initially participants were only included if they had received a c-section to give birth. It became clear during recruitment that this was limiting, as some women had been denied this option and although this was addressed with a change in the inclusion criteria, it happened too late for it to have an impact on recruitment.

2.4.4 Recommendations for further research

In keeping with the methodological limitations of the research, it is recommended that future research aims to explore the experience and prevalence of primary tokophobia in women from marginalised groups within the UK, this is further discussed in Chapter 3. This would facilitate further understanding as to how and whether primary tokophobia is represented in different social groups of women. Additionally, it would provide insight into the existence of any cultural subtleties associated with the experience.

Furthermore, it is recommended that research is conducted utilising a longitudinal design, interviewing the same women at different time points. This could be completed through the use of interviews or by analysing the content of women's posts on online support forums over time. This would help extend knowledge about

the development and evolution of tokophobia, adding value to the current research in utilising a robust methodological approach (Coolican, 2017; Gosling & Mason, 2015).

2.5 Conclusion

This in-depth qualitative study has contributed to the empirical evidence base concerning women's experience of tokophobia that presents before the birth of the first child. Primary tokophobia, while currently construed as an anxiety disorder, is indicative of a life transition that causes distress in the context of systems that are unable to support this, while women attempt to find ways to manage this conflict. Its existence or impact may be limited if the systems surrounding women adopt a more holistic approach to considering childbirth and the transition to motherhood.

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Chapter 3: Reflective paper

My lived research experience: Reflections on the process

Overall word count (excluding references): 3051

3.0 Introduction

This chapter serves to provide a reflective account of my experiences during the completion of my research papers exploring tokophobia and miscarriage. Whilst, I have found the reflective focus on clinical training to be a helpful tool in my development personally and as a practitioner, I have been surprised that this extends into the research context. The reflections detailed within this account are informed by insights from the reflective diary kept during the research process. They have been selected as they represent a collection of issues that had particular salience in the research process and had meaning both clinically and personally. As such, they reflect my constructivist epistemological position, which seeks to identify how issues are socially created and maintained, therefore matters broadly pertaining to this are discussed in relation to recruitment processes, interviews, language and the concept of motherhood (Burr, 2003; Crotty, 1998). A formal model has not been explicitly used, however my reflections have been guided by Gibbs (1988) reflective cycle which focuses on providing a description and analysis of the event and then considers future actions based on the evaluation.

3.1 Recruitment: Marginalisation and responsibility

The sense of disenfranchisement that arose in the narratives of participants in the empirical paper, encouraged me to reflect upon issues of marginalisation and power within the research process.

It is notable that all of the women that took part in the empirical paper identified as White-British, were employed, formally educated to a minimum of G.C.S.E level (although for most it was to degree level) and were in heterosexual long-term relationships. Similarly, participants in the systematic paper reflected a white

middle-class population. Therefore, the extent to which tokophobia and miscarriage effects other groups of society remains unknown. As I recognised the shared limitation in both studies, I began to question why people in non-dominant social groups (e.g. being of non-white ethnicity, low socio-economic, non-heterosexual), do not participate in research.

To facilitate my understanding, I considered the studies' recruitment strategy. This was constructed to ensure I could recruit sufficient numbers of women that identified as having a severe fear of childbirth within the time-scale of the thesis and focussed on recruitment through the National Health Service (NHS) and an online forum.

Neglectfully, I did not contemplate whether these strategies would ensure women from a range of social backgrounds were included in the research. I implicitly assumed most people have access to healthcare and the internet although intellectually I know this is not the case; having developed an awareness through my education and clinical experience, that factors such as education, disability, ethnicity and socio-economic status act as barriers to people having equitable access to healthcare or technology (Marmot et al., 2010; Office for National Statistics, 2015).

Nevertheless, despite having an understanding of these issues, I failed to consider this in my research planning. This lack of foresight indicates my position of privilege as an educated woman, in seeing the world through my own assumptions and biases (Berger, 2013). I found this a particularly uncomfortable truth to acknowledge, given my personal identification as a mixed-race, politically and socially aware woman who tries to promote equality. Importantly this issue in my recruitment has highlighted I have a significant amount to learn regarding the complexities of unintentional biases, its impact on oppression and its manifestation in research. As Sue (2010) explains, if minority groups are not included in research then reality,

knowledge and understanding are constructed solely on the basis of the dominant group's experience (e.g. white, middle class and heterosexual), which denies the non-dominant group power. Thus, with the lack of inclusivity of minority social groups being reported as a wider issue within women's psychological research, if research is to truly reflect the experiences of society, it is imperative for researchers to be aware of their own biases (Etaugh & Bridges, 2015; Hall, 2003). Therefore, my current experience has helped me to gain an enhanced sensitivity towards my own intersects of power as a trainee clinical psychologist, including its associated blind-spots, which will hopefully enable me to work more thoughtfully and take active strategies to reduce social injustice which I see as a vital component of psychology (Teo, 2015).

There is no definitive solution to achieving this, with sensitivity and creativity needing to be applied to each research project (Etaugh & Bridges, 2015). Reflecting on my thesis recruitment, I wonder if adopting multiple research strategies, including conducting an online focus group, may have encouraged participation from a wider demographic.

Additionally, awareness of the underrepresentation of different sociodemographic groups has implications for my clinical practice. I will now be more discerning to whether clients entering the service are reflective of the local demographic and if not, I will feel more empowered to attempt to rectify this issue. This could be approached by trying to understand the specific needs of communities to facilitate engagement and trying to embed members of the communities within the decision-making process regarding services (NHS Confederation, 2013).

3.2 Reciprocity: Exploring the researcher and clinician conflict

Engaging in the research interviews was an interesting experience, however, I found it challenging to manage the researcher - clinician balance. Prior to interview commencement, I had assumed that this would have been one of the easier parts of completing the research, as conducting interviews is part of my clinical role. However, it raised a number of personal and ethical issues that required consideration.

Whilst I initially felt at-ease and excited to meet the participants, once the dictaphone was turned on I felt a change in myself. Despite a genuine curiosity about what the participants were saying, at times I felt myself feeling self-conscious, over-thinking questions and feeling guilty for asking them. Whilst women were talking, I noticed that I was starting to formulate, identifying women's defences against the emotions they were experiencing or defences against forming a relationship with me, which was understandable given the brief nature of our relationship (Frederickson, 2013). In keeping with my favoured psychological approach, I wanted to draw attention to these strategies and explore them, as I felt it would be helpful for ensuring the data gathered in the interview was meaningful, but primarily because I deemed it may be useful in helping the participants to make sense of their tokophobia. However, I persisted with the interview schedule.

Consequently, both during and following the interviews I felt ethically compromised, which I attribute to the vastly different roles of being a researcher and a clinician. During the interviews, I was primarily guided by the concept of avoiding and minimising harm (British Psychological Society [BPS], 2014). Therefore, part of my decision-making about my approach in interviews, was that participants had

consented to participate in research, not to therapy and that if I were to ask challenging questions or articulate things I had noticed, I would be breaching this boundary. However, the conflict arose as I felt a distinct power dynamic within the interviews. I was in peoples' homes, recognising their vulnerabilities as they told of their difficult and sometimes painful life experiences. Yet despite the inclusion of a debrief following the interview, I was not offering the same level of emotional support as I would in my clinical role; I felt I was withholding knowledge, which felt ethically questionable. This made the BPS guidance become unclear, as I contemplated how much harm was I minimising if I was not trying to help as my skills may have afforded?

In order to make sense of my dissatisfaction with this aspect of the interviews, I came across literature on reciprocity in qualitative research, which describes the desire for researchers to give something back to participants in interviews (Mertens, 2014; Morse, 2015). It helped to illustrate this was an ethically complex area and encouraged evaluation of the research role from a different perspective. Proponents of the approach suggest that it is the responsibility of the researcher to conduct their study in a manner that is personally beneficial for participants, by asking questions that raise participants' consciousness within their situations and challenges dominant discourses (Mertens, 2014; Morse, 2015).

Furthermore, the literature also highlighted the importance of the researcher sharing something of themselves in the interviews, which was an issue I'd additionally found challenging. In initial interviews, I had volunteered very little of myself, but it felt disingenuous not to declare my motherhood, that I'd been through childbirth and explain why I was interested in conducting the research, thus I started to incorporate this into subsequent interviews. It is suggested this is important in providing

participants with power within the interview process, as in understanding the researcher's position they can evaluate their line of inquiry and interpretations, correcting any misunderstandings (Larson, 1997). I found this stance reassuring, as it provided another perspective on the BPS (2014) 'minimal harm' guidance, which fitted with my constructivist epistemological position in addition to my humanity.

In reevaluating the interviews, despite feeling restricted in them, I was pleased to see that some participants may have gained some benefit from the process. During the debrief of one interview, a participant spoke of her plans to find out further information about birth methods and seek psychological support. Additionally, on the online forum, despite having no contact with participants, I was able to follow their journey following the interview; noting the two nulliparous women had become more active and were exploring ways to help them conceive (it is noted that these actions may not be as a direct result of the interview). Consequently, conducting the interviews has encouraged me to develop my understanding of the complexity of ethical matters when conducting research. In deepening my experience of this, I have a better awareness of my own position on this matter, which will inform my conduct in future interviews as I will know more about my motives when making specific choices and decisions.

3.3 Finding a common language to communicate

Throughout the research process, I encountered experiences which highlighted the complexity and challenges of language in relation to the construction of mental health experiences.

The difficulties with language became apparent during recruitment when potential participants were uncertain if they had 'primary tokophobia', whilst the description

of severe fear of childbirth present before the birth of the first child resonated with their experiences, many had not heard of the label. This was further confounded in the interviews when women spoke of the utility of the label. This was mixed with some women finding it helpful, overwhelmingly however, participants did not agree with their experience being constructed as ‘abnormal’ or ‘illogical’. This epitomises the concerns expressed by the BPS (2011) regarding the “*continued and continuous medicalisation*” (p.2) of natural responses to experiences. Following the research, I proposed that tokophobia is experienced when women contemplate or begin their transition into motherhood, experiencing internal conflicts in a society that does not provide the space for these to be sufficiently explored or understood. This presented further challenges and confusion in writing up the paper, as I was using a label to convey a language and experience, that I no longer felt was entirely constructive or reflective of participants’ experiences. This presented a professional conflict, as Burr (2003) suggests:

“Language provides the basis for all our thought. It provides us with a system of categories for dividing up our experience and give it meaning, so that our very selves become the product of our language” (p.62).

Hence, I was mindful of my power professionally, in using a language that contributed to the further disenfranchisement of the participants and encouraged their identification as ‘outsiders’, which contrasts with my aims as a trainee psychologist, meant to support and empower people (BPS, 2017). However, equally it felt necessary to adopt a language that medical professionals (e.g. obstetricians, midwives and general practitioners) would understand as they are gatekeepers to women’s healthcare and represent one of the key target audiences for the research

(Burr, 2003). Therefore, their engagement would help the research findings translate into clinical practice, giving it greater power in improving care for women with severe fear of childbirth.

This conflict fits broadly with my experience and development over the course of the doctorate. As my understanding of mental health experiences becomes more nuanced through formulation, my disillusionment with the dominant model of diagnostic labelling grows. However, I also must acknowledge that this is my perception and my frame of reference, with some individuals finding labels reassuring as they normalise their experience, which was evident in the current research and in clinical practice (BPS, 2011). Therefore, for me to impose my philosophy and preference for psychological formulation upon people could be deemed as oppressive as only utilising diagnostic labels (Love, 2018).

Considering what this means for my future clinical practice is unclear. Potentially, I will have to learn to hold two positions, firstly in ascertaining how clients identify their mental health and the meaning they give to a diagnostic label, while working with them through formulation to provide additional understanding of their difficulties. Yet when working with my medical colleagues, I may need to refer to diagnostic language while specifying my interpretation of it informed by psychological formulation.

3.4 The construction of motherhood: Parallels in research and life

Conducting the systematic and empirical research, promoted my consideration of the complexity of motherhood. This was unexpected as although I had chosen two topics related to women and pregnancy, I had naively failed to anticipate that the transition

to motherhood would be a fundamental feature of both experiences until I started analysing the data for both papers and constructed the discussion.

Consequently, I have considered the role and value placed upon mothers in our society. There is a strong narrative presented in wider society, that implies women should and can have it all, including successful careers, being 'super' mums and attentive partners (Choi, Henshaw, Baker, & Tree, 2005). This message is presented in the media, by celebrity culture and by women themselves, who do not want to appear as 'failing' (Abetz & Moore, 2018; Choi et al., 2005; Douglas & Michaels, 2005). The discourse is also perpetuated in the workplace, with only 19 percent of British working mothers reporting being able to take advantage of flexible working conditions, despite it being promoted at policy level (Institute for Public Policy, 2014). This suggests the demanding role of motherhood is often not recognised by society, with women often being perceived as able to juggle multiple roles with equal success and limited adaptations.

The psychological literature presents a different perspective of motherhood, providing understanding about the changes women experience. For instance, in the transition to motherhood, women's consciousness expands cognitively and emotionally to incorporate their children into their identities (Laney, Hall, Anderson, & Willingham, 2015). This is further supported by evidence highlighting that women's brains undergo structural change following pregnancy, which is proposed to reflect the adaptations required to provide care and attention to a child (Hoekzema et al., 2016). These changes are vital in ensuring that mothers are sensitive caregivers and attuned to their children's needs, in order to ensure their survival and development (Bion, 1962; Bowlby, 1983)

As I reflect upon these dichotomies, it is evident that my own experience parallels the internal and external conflicts experienced by the participants involved in the empirical paper. My experience during clinical training has been characterised by a transition into motherhood, due to giving birth to my son in the first year and becoming pregnant during the write-up of my thesis. However, I attempted to preserve my pre-motherhood identity to show myself, the course and wider society that I was still 'capable'. I simultaneously tried to be the 'perfect' parent, in accordance with the psychological knowledge I was gaining (O'Reilly, 2014). The impact of this was immense guilt as I felt that I was not meeting any of my standards sufficiently. Intellectually, I understood my life had changed practically with motherhood, but I was not open to wholly accepting this meant that my identity and subsequently, my focus had changed. This may be partially attributable to a fear that I would not 'survive' the doctorate if my standards relented.

Now considering this from a place of safety, with the doctorate near-ending, I recognise that this reflected my greatest personal learning. The research papers have broadened my understanding of what a mother is, to include women both with and without children, along with an understanding of the challenges the role brings.

Applying this knowledge to the clinical setting, I believe I have a deeper understanding of the challenges that may be presented in therapy, with some women struggling to focus on themselves and the therapeutic process due to their mental and emotional space being occupied by another. Personally, I recognise I have been through a process of developing understanding of my new identity as a mother; this means my expectations of myself need to adjust accordingly, which doesn't make me any more of a success or failure. Whilst I know this will continue to be challenging at times, I hope that I am able to take this new-founded belief forward into my future

employment to ensure I am achieving in the area I consider to be most important, as a mother.

3.5 Conclusions

It is apparent that completing two papers that adopt qualitative methodologies have afforded a rich learning experience. I now realise both the beauty and challenge of research, is that you may have pre-conceptions regarding what the exploration will unveil, but these are often misguided. In reflecting on the research process, in line with my social constructivist epistemology, it is evident that there are many opportunities to challenge and question assumptions of oppression, power and responsibility, in both research and clinical practice. I recognise there is no definitive answer, just the process of exploring how our present truths are constructed and the impact these have on individuals. At the start of clinical training this would have filled me with terror however, I now feel both curious and excited to take this knowledge forward. I am keen to further knowledge of myself, my assumptions and beliefs, to try and understand the lives of others and reciprocally, expanding knowledge of myself through learning about the lives of others. As Yalom aptly summarised:

“Your greatest instrument is you, yourself, and the work of self-understanding is endless. I'm still learning.” (p.167).

3.6 References

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Appendices

Appendix A: Author guidelines: Journal of Reproductive and Infant Psychology

Preparing Your Paper

Word Limits

Please include a word count for your paper. A typical paper for this journal should be no more than 3500 words.

Style Guidelines

Please refer to these quick style guidelines when preparing your paper, rather than any published articles or a sample copy. Please use British (-ise) spelling style consistently throughout your manuscript.

Formatting and Templates

Papers may be submitted in Word or LaTeX formats. Figures should be saved separately from the text. To assist you in preparing your paper, we provide formatting template(s). Word templates are available for this journal. Please save the template to your hard drive, ready for use. A LaTeX template is available for this journal. Please save the LaTeX template to your hard drive and open it, ready for use, by clicking on the icon in Windows Explorer.

If you are not able to use the template via the links (or if you have any other template queries) please contact us [here](#).

References

Please use this reference guide when preparing your paper. An EndNote output style is also available to assist you.

Checklist: What to Include

Author details. Please ensure everyone meeting the International Committee of Medical Journal Editors (ICMJE) requirements for authorship is included as an author of your paper. All authors of a manuscript should include their full name and affiliation on the cover page of the manuscript. Where available, please also include ORCiDs and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors' affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. Read more on authorship.

Should contain a structured abstract of no more than 250 words.

Graphical abstract (optional). This is an image to give readers a clear idea of the content of your article. It should be a maximum width of 525 pixels. If your image is narrower than 525 pixels, please place it on a white background 525 pixels wide to ensure the dimensions are maintained. Save the graphical abstract as a .jpg, .png, or .gif. Please do not embed it in the manuscript file but save it as a separate file, labelled GraphicalAbstract1.

You can opt to include a video abstract with your article. Find out how these can help your work reach a wider audience, and what to think about when filming.

Between 5 and 6 keywords. Read making your article more discoverable, including information on choosing a title and search engine optimization.

Funding details. Please supply all details required by your funding and grant-awarding bodies as follows:

For single agency grants

This work was supported by the [Funding Agency] under Grant [number xxxx].

For multiple agency grants

This work was supported by the [Funding Agency #1] under Grant [number xxxx]; [Funding Agency #2] under Grant [number xxxx]; and [Funding Agency #3] under Grant [number xxxx].

Disclosure statement. This is to acknowledge any financial interest or benefit that has arisen from the direct applications of your research. Further guidance on what is a conflict of interest and how to disclose it.

Geolocation information. Submitting a geolocation information section, as a separate paragraph before your acknowledgements, means we can index your paper's study area accurately in JournalMap's geographic literature database and make your article more discoverable to others. More information.

Supplemental online material. Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about supplemental material and how to submit it with your article.

Figures. Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour, at the correct size). Figures should be supplied in one of our preferred file formats: EPS, PS, JPEG, GIF, or Microsoft Word (DOC or DOCX). For information relating to other file types, please consult our Submission of electronic artwork document.

Tables. Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.

Equations. If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about mathematical symbols and equations.

Appendix B: Coventry University Certificate of Ethical Approval: Paper 1



Certificate of Ethical Approval

Applicant:

Eleanor Gunn

Project Title:

Systematic review: the psycho-social processes involved in pregnancy loss.

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Medium Risk

Date of approval:

26 March 2018

Project Reference Number:

P69356

Appendix C: Quality assesment checklist

QualSyst Quality Assessment Checklist for Qualitative Research (Adapted from Kmet et al., 2004)

Criteria	Yes	Partial	No
1. Question/objective sufficiently described?			
2. Study design evident and appropriate			
3. Context for the study clear?			
4. Connection to a theoretical framework/wider body of knowledge?			
5. Sampling strategy described relevant and justified?			
6. Data collection methods clearly described and systematic?			
7. Data analysis methods clearly described and systematic?			
8. Use of verification procedure (s) to establish credibility?		N/A	
9. Conclusions supported by the results			
10. Reflexivity of the account			

Appendix D: Kappa inter-rater reliability coefficient scores

Overall inter-rater reliability scores

		Symmetric Measures			
		Value	Asymptotic Standard Error ^a	Approximate T ^b	Approximate Significance
Measure of Agreement	Kappa	.815	.080	8.780	.000
N of Valid Cases		70			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Carolan and Wright (2017) paper:

		Symmetric Measures			
		Value	Asymptotic Standard Error ^a	Approximate T ^b	Approximate Significance
Measure of Agreement	Kappa	1.000	.000	3.162	.002
N of Valid Cases		10			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Meaney et al. (2017) paper:

		Symmetric Measures			
		Value	Asymptotic Standard Error ^a	Approximate T ^b	Approximate Significance
Measure of Agreement	Kappa	.756	.227	3.266	.001
N of Valid Cases		10			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Batool & Azam (2016) paper:

		Symmetric Measures			
		Value	Asymptotic Standard Error ^a	Approximate T ^b	Approximate Significance
Measure of Agreement	Kappa	.756	.227	3.266	.001
N of Valid Cases		10			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Simmons et al. (2006) paper:

		Symmetric Measures			
		Value	Asymptotic Standard Error ^a	Approximate T ^b	Approximate Significance
Measure of Agreement	Kappa	.630	.243	2.509	.012
N of Valid Cases		10			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Gerber-Epstein et al. (2008) paper;

		Symmetric Measures			
		Value	Asymptotic Standard Error ^a	Approximate T ^b	Approximate Significance
Measure of Agreement	Kappa	1.000	.000	3.162	.002
N of Valid Cases		10			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Harvey et al. (2001) paper:

		Symmetric Measures			
		Value	Asymptotic Standard Error ^a	Approximate T ^b	Approximate Significance
Measure of Agreement	Kappa	.630	.321	2.799	.005
N of Valid Cases		10			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Adolfsson et al. (2004) paper:

		Symmetric Measures			
		Value	Asymptotic Standard Error ^a	Approximate T ^b	Approximate Significance
Measure of Agreement	Kappa	1.000	.000	4.135	.000
N of Valid Cases		10			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

Appendix E: Quality assesment criteria scores

Quality Criteria	Study	Carolan & Wright, 2017	Meaney et al. 2017	Batool & Azam, 2016	MacWilliams, et al. 2016	Andersson, et al. 2012	Adolfsson, 2010	Hamama-Raz, et al. 2010.	Gerber-Epstein et al. 2008	Simmons et al. 2006	Swanson et al. 2007	Adolfsson et al. 2004	Maker & Ogden, 2003	Harvey et al. 2001
Objective described		2	2	2	2	2	2	2	2	2	2	2	1	2
Study design evident and appropriate		2	2	2	2	1	2	2	2	1	2	2	1	2
Context for study clear		1	2	2	1	2	2	2	2	2	1	1	2	2
Connection to theoretical framework/body of knowledge		2	1	2	2	2	1	2	2	1	2	2	2	2
Sampling strategy relevant and justified		1	1	1	2	2	1	1	2	2	2	1	2	2
Data collection methods described & systematic		2	2	1	2	2	1	2	2	2	2	2	2	2
Data analysis described & systematic		2	2	2	2	2	1	2	2	1	2	2	2	2
Verification procedures to establish credibility ⁶		2	2	2	2	2	0	2	2	2	0	2	0	2

⁶ Can only score 0 or 2

Conclusions supported by results	2	2	2	2	2	2	2	2	2	2	2	2	1
Reflexivity of account	2	0	0	0	0	0	1	0	0	0	0	0	0
Total score	17	16	16	17	17	12	18	18	15	14	16	14	17

Note: degree to which quality criteria is met: 0 = no, 1= partial, 2 = yes

Appendix F: Coventry University certificate of ethical approval: Paper 2



Certificate of Ethical Approval

Applicant:

Eleanor Gunn

Project Title:

Women's lived experience of primary tokophobia

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as High Risk

Date of approval:

23 May 2017

Project Reference Number:

P53066

Appendix G: NHS ethical approvals

HRA approval



Health Research Authority

Ms Eleanor Gunn
Trainee Clinical Psychologist
Coventry and Warwickshire Partnership NHS Trust
St Micheal's Hospital
St Micheal's Road
Warwick
CV34 5QW

Email: hra.approval@nhs.net

28 July 2017

Dear Ms Gunn,

Letter of HRA Approval

Study title:	Women's lived experience of primary tokophobia
IRAS project ID:	225936
REC reference:	17/EE/0279
Sponsor	Coventry University

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS [organisations in](#) England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document “*After Ethical Review – guidance for sponsors and investigators*”, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](http://www.hra.nhs.uk), and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](http://www.hra.nhs.uk).

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application

IRAS project ID	225936
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procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is **225936**. Please quote this on all correspondence.

Yours sincerely

Alex Thorpe
Senior Assessor

Email: hra.approval@nhs.net

*Copy to: Prof Olivier Sparagano, Sponsor's Representative
Ms Jo Williams, South Warwickshire NHS Foundation Trust, Lead R&D Contact*

Research Ethics Committee Approval



East of England - Essex Research Ethics Committee

The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

28 July 2017

Ms Eleanor Gunn
Trainee Clinical Psychologist
Coventry and Warwickshire Partnership NHS Trust
St Micheal's Hospital
St Micheal's Road
Warwick
CV34 5QW

Dear Ms Gunn

Study title:	Women's lived experience of primary tokophobia
REC reference:	17/EE/0279
IRAS project ID:	225936

Thank you for your letter of 24 July 2017 responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Copies of advertisement materials for research participants [poster]	1.0	22 March 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Professional Indemnity]	1.0	05 August 2016
GP/consultant information sheets or letters [GP letter]	2.0	04 April 2017
Interview schedules or topic guides for participants [Interview schedule]	2.0	19 July 2017
Interview schedules or topic guides for participants [Interview schedule - clean version]	2.0	19 July 2017
IRAS Application Form [IRAS_Form_19062017]		19 June 2017
Letter from sponsor [Sponsor letter]	1	23 May 2017
Letters of invitation to participant [NHS invitation letter]	1.0	02 May 2017
Non-validated questionnaire [Demographic questionnaire]	1.0	22 March 2017
Non-validated questionnaire [inclusion/exclusion screening questionnaire]	2.0	04 April 2017
Other [Certificate of employers liability insurance]	1.0	01 August 2016
Other [certificate of ethical approval]	1.0	23 May 2017
Other [External feedback on research proposal page 1]	1.0	04 October 2016
Other [External feedback on research proposal page 2]	V.1.0	04 October 2016
Other [Sarah simmonds email re c.v.]	1.0	19 July 2017
Other [IRAS cover letter]	1.0	24 July 2017
Participant consent form [Participant consent form]	2.0	11 April 2017
Participant information sheet (PIS) [Patient Information sheet]	3.0	19 July 2017
Participant information sheet (PIS) [Participant information sheet - clean version]	3.0	19 July 2017
Referee's report or other scientific critique report [Ethics review report]	1	24 May 2017
Research protocol or project proposal [Research protocol]	3.0	11 April 2017
Summary CV for Chief Investigator (CI) [C.V]	1.0	07 June 2017
Summary CV for student [C.V]	1.0	07 June 2017
Summary CV for supervisor (student research) [Jo CV (supervisor)]	2.0	24 July 2017
Summary CV for supervisor (student research) [sarah c.v (supervisor)]	1.0	07 June 2017
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Research protocol flowchart]	1.0	09 June 2017

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at


<http://www.hra.nhs.uk/hra-training/>

17/EE/0279

Please quote this number on all correspondence
--

With the Committee's best wishes for the success of this project.

Yours sincerely



Dr Niki Bannister
Chair

Email:



Enclosures:

"After ethical review – guidance for
researchers"

Copy to:

*Prof Olivier Sparagano
Ms Jo Williams, South Warwickshire NHS Foundation Trust*

Appendix H: Local trust approval

Subject: IRAS 225936. Confirmation of Capacity and Capability at South Warwickshire NHS Foundation Trust

Dear Eleanor,

RE: IRAS 225936. Confirmation of Capacity and Capability at South Warwickshire NHS Foundation Trust.

Full Study Title: Women's lived experience of Primary Tokophobia.

This email confirms that South Warwickshire NHS Foundation Trust has the capacity and capability to deliver the above referenced study. Please find attached our agreed Statement of Activities as confirmation.

We agree to start this study on a date to be agreed when you as sponsor give the green light to begin.

If you wish to discuss further, please do not hesitate to contact me.

Many Thanks

Kerrie Webb

Assistant Manager for Research

Room 110, Medical Education Building

South Warwickshire NHS Foundation Trust

Lakin Road

Warwick

CV34 5BW

Tel: [REDACTED]

Appendix I: Eligibility criteria screening



Inclusion/exclusion criteria screen

Title of Project: Women's Experiences of Primary Tokophobia

Name of Lead Researcher: Eleanor Gunn, Trainee Clinical Psychologist

The following questions are there to see if you meet the criteria to participate in the current research. Please answer these questions as fully as possible; if there are any questions you do not understand please let the researcher know.

Primary tokophobia screen:

- 1) Would you describe yourself as having a severe fear of pregnancy and/or childbirth?
Yes ☐ No ☐ Unsure ☐

- 2) Would you describe your fear as being beyond ordinary concerns about pregnancy and/or childbirth?
Yes ☐ No ☐ Unsure ☐

- 3) Have you taken additional steps to avoid pregnancy and/or childbirth because of this fear? (such as: contraception, avoidance of intimacy, sterilisation, termination or caesarean)
Yes ☐ No ☐ Unsure ☐

- 4) If you have had a child, how was your baby delivered? (e.g. naturally, caesarean, ventouse cap, forceps). How did you request its delivery ?

5) If you have a child/children, were you aware of your severe fear of pregnancy before the delivery of your first child?

Yes ☐ No ☐

6) Please describe your gender

7) Date of birth: dd/mm/yyyy

8) Are you fluent in English?

Yes ☐ No ☐

9) If you have children, what are their ages?

10) If you have had children, what country were they born in?

11) Are you currently pregnant? *(If you are currently pregnant we will need to check that are perinatal services within your area that support women with severe fear of childbirth)*

Yes ☐ No ☐

12) Please provide your current address:

13) Do you experience any difficulties with your mental health or wellbeing, other than your fear of childbirth?

Yes ☐ No ☐

Please describe the nature of these difficulties:

14) Have you attempted suicide in the last 12 months?

Yes ☐

No ☐

15) Have you attempted to harm yourself physically in the last 12 months?

Yes ☐

No ☐

16) Please provide the details of your GP:

Appendix J: Demographic questionnaire



These questions will help us to understand some of the background of the participants who have taken part in the research, please complete as fully as you feel comfortable and are able.

Please describe your ethnicity

.....

Please select your current relationship status:

Single ☐ Married ☐ cohabiting ☐ In a relationship & not
cohabiting ☐

Other (*please describe*)

Please select your highest/final level of education:

primary school	<input type="checkbox"/>	Secondary school	<input type="checkbox"/>
GCSE or equivalent	<input type="checkbox"/>	A-level or equivalent	<input type="checkbox"/>
undergraduate degree or equivalent	<input type="checkbox"/>	Postgraduate-masters or equivalent	<input type="checkbox"/>
post-graduate -doctorate or equivalent	<input type="checkbox"/>		

Other (*please describe*)

Please select your current employment status:

Unemployed ☐ student ☐ employed – part time ☐ employed-
fulltime ☐

Other (*please describe*)

Please select the annual household income level that best matches yours:

- | | | | |
|------------------|--------------------------|-------------------|--------------------------|
| £0-£10,000 | <input type="checkbox"/> | £30,001-£40,000 | <input type="checkbox"/> |
| £10,001-£20,000 | <input type="checkbox"/> | £40,001-£50,000 | <input type="checkbox"/> |
| £20,001-£30,000 | <input type="checkbox"/> | £50,001 -£60,000 | <input type="checkbox"/> |
| £60,001- £70,000 | <input type="checkbox"/> | £70,001- £100,000 | <input type="checkbox"/> |
| £ £100,001 + | <input type="checkbox"/> | | |

Appendix K: Interview guide



Semi-structured interview guide

Title of Project: Women's Lived Experience of Primary Tokophobia

Name of Lead Researcher: Eleanor Gunn, Trainee Clinical Psychologist

Thank-you for agreeing to take part in the research and meeting with me today. I am going to ask you a series of questions related to pregnancy and childbirth please answer these as you feel able, if at any time you feel or uncomfortable or would like to pause for a break or to end the interview please let me know.

Before we start I would like to remind you, as outlined in the Information Sheet, your contribution to the research will be kept confidential unless the researcher has concerns about the safety of you, anyone associated with you or is made aware of any professional malpractice by health professionals, in which case confidentiality may be broken. All data will be anonymised however where direct quotes are used in the write-up of the research, every effort to maintain confidentiality will be used however this cannot be guaranteed. Are you happy to continue?

These questions are a guide and may change as the interviewer feels is appropriate. Prompt questions only to be used if participant struggles to answer the opening question.

1. *Can you tell me a bit about yourself?*
2. *Can you tell me about your views and/or experience of pregnancy and childbirth?*

Prompts: what does/would being pregnant or giving birth mean to you? when did you first notice your anxiety about childbirth and pregnancy? what sense did you/do you make of it?

3. Can you tell me what it was like/is like having xxxx (use their words to describe it e.g. severe fear of child birth) ?

Follow up questions:

- a) Day-to-day (**all participants**)

- b) When thinking about having a baby/planning to have a baby (**all participants**)

Additional Prompts; what did you do to decide; what were your thoughts/feelings

- c) During pregnancy/when pregnant (**Participants who indicate they have been pregnant previously**)

Additional prompts: what was your response to finding out you were pregnant; what were your thoughts/feelings during pregnancy, in what ways did you notice your fear during pregnancy; what sense of it during pregnancy; what was your engagement with the process; did you seek support and why

- d) During labour/delivery (**Participants who indicate they have children**)

Additional prompts; what type of birth did you have; what was it like going into hospital; what were your thought/feelings/behaviours during this time

- e) The first 6-12 months after the birth (**Participants that indicate they have children**)

Additional prompts: what was it like being a new mum; what were your thoughts/feelings about being a parent; what were your thoughts and feelings about your baby; what sense did you make of your fear of childbirth.

4. What has having severe fear of childbirth meant for you? (**All participants**)

Prompts: your close relationships (Friends, family, children, partner, dating, intimacy); the way you see yourself /who you are? opportunities? Challenges?

5. Did you have any other thoughts and comments that we haven't covered about your experiences ? **(all participants)**

Appendix L: Recruitment poster



Do you have experience of severe fear of pregnancy or childbirth?

I am inviting women, that have experience of a severe and disabling fear of childbirth that developed before they had given birth (known as primary tokophobia), to take part in research looking at their experiences. The research is being carried out as part of a Doctoral thesis for Coventry University and the University of Warwick.

I would like to talk with women who:

- may have decided not to have children, be currently pregnant or already have children
- had this experience within the last five years
- currently based in England
- over the age of 18

What would taking part mean?

Taking part would involve you meeting with me and sharing your perspective in individual interviews lasting approximately an hour. The findings of the research aim to improve knowledge and support for woman who experience primary tokophobia.

If are interested and would like more information

Please contact me - Eleanor Gunn, Lead Researcher
email: [REDACTED]

Appendix M: Participant invitation letter



Department of Clinical Health Psychology

Date

Warwick Hospital

Address

Lakin Road
Warwick
CV34 5BW

Tel: [REDACTED]

Fax: [REDACTED]

Email: [REDACTED]

Dear XXXX

I am writing to let you know about a new research study. The research is looking at women's experience of primary tokophobia (a severe and disabling fear of childbirth which appears before the birth of the first child). I am contacting you and all the women I (or my colleagues) have seen in the last five years who I have supported through this experience to ask if you would be willing to be involved in the research.

The research is being carried out by Ms Eleanor Gunn, Trainee Clinical Psychologist at the Universities of Coventry and Warwick. She would like to hold individual interviews with women who are willing to share their experiences of primary tokophobia. We hope that the research findings will be used to increase awareness of primary tokophobia and help improve support for the condition.

Taking part in research is voluntary and if you would prefer not to participate this will have no impact on any current or future treatment. If you think you might be willing to participate, I would like to give your contact details to Eleanor; she will then contact you to provide you with further details. In this case, please either ring the department or email (details above) to let me know. Alternatively, you are welcome to contact Eleanor directly (her details are at the end of this letter). The initial contact with Eleanor doesn't mean you have to take part in the study, but will just give you the opportunity to find out more about what is involved.

If I have not heard from you within two weeks from the date of this letter, I will follow-up with a telephone call to see if this is an opportunity you are interested in.

I look forward to hearing from you.

With best wishes,

Dr Kirstie McKenzie-McHarg
Consultant Clinical Psychologist (Women and Children)

Appendix N: Participant information sheet



Participant Information Sheet

Study title: Women's lived experience of primary tokophobia

Lead Researcher: Eleanor Gunn, Trainee Clinical Psychologist

I would like to invite you to take part in a research study which look at women's experiences of a severe and disabling fear of childbirth which starts before a woman has given birth for the first time, known as primary tokophobia. *Joining the study is entirely up to you, before you decide I would like you to understand why the research is being done and what it would involve for you.* Please take time to read this Information Sheet carefully; talk to others about the study if you wish and ask me if there is anything that is not clear. *The Information Sheet tells you the purpose of the study and what will happen to you if you take part.*

What is the purpose of the study?

The aim of the study is to explore women's experience of primary tokophobia, using individual interviews. Currently there is very little UK-based research aimed at exploring what it is like to have primary tokophobia. It is hoped this will help to increase understanding and awareness of primary tokophobia, with the intention of improving support for women who experience the condition. The research data generated will be used primarily to contribute to a Doctorate in Clinical Psychology and may be published in future.

Why have I been invited?

You are being invited as you have indicated that you identify with experiencing a severe fear of childbirth that you were aware of either before pregnancy, during your first pregnancy or if you have children, before the birth of your first child.

Do I have to take part?

Participation is entirely voluntary therefore, it is up to you to decide whether or not you would like to take part. If you decide not to take part in this study it will not affect any treatment you receive now or in future.

Please read through this information sheet. If you are interested in taking part in the research or in finding out more about it, I would be grateful if you could let me know by contacting me, my contact details are at the end of this sheet.

What will happen to me if I take part?

If you decide to take part, you will be asked to complete a consent form. Following your consent to participate you will be asked to complete short questionnaire to ensure you meet the criteria for the study, which includes:

- Be aged 18 and over;
- Experienced primary tokophobia within the last five years;
- Be living in England
- If you have children your oldest child must 5 years old or younger;
- If you have given birth, to have given birth in the UK;
- If pregnant, you must have access to NHS support locally for primary tokophobia (which will be established by the lead researcher);
- Fluent in English
- No attempts of suicide or self-harm in the last year.

If you meet the criteria and have been recruited through the NHS or you are currently pregnant your GP will automatically be informed of your participation. If the researcher has concerns about the safety of anyone that either participates in the research or is associated with someone who participates in the research, their GP or other relevant agencies, may be informed.

You will be invited to attend an interview and the lead researcher will work with you to establish a suitable time and place for the interview. There may be the possibility of arranging a video interview, such as skype, if a convenient venue for the interview cannot be arranged.

The interview will last for approximately 45- 90 minutes. At the interview the researcher will let you know how the time will be structured and provide you with an opportunity to ask any questions. The researcher will check you still agree to take part and then ask you to complete some questions about your background, then she start the interview, all of which will be audio-recorded.

The researcher will contact you a few days before your scheduled interview to remind you of your appointment. If you are no longer able to make it, you can let the researcher know.

Expenses and inconvenience allowance

You will not be paid to participate in the study.

What are the possible benefits of taking part?

Some people find discussing personal experiences helpful and rewarding, but this is not guaranteed. The information gained from your participation in the study will help to improve knowledge about primary tokophobia. The findings of the research may also be used to inform support provided by services, such as the NHS, for women with tokophobia.

What are the possible disadvantages and risks of taking part?

Whilst we do not anticipate that the interview questions will elicit unmanageable distress, it is natural that for some people sharing personal experiences may increase feelings of distress before, during or after the interview.

You will not be expected to answer any questions you do not feel comfortable answering and the interviewer will aim to support you to keep the discussion of your experiences at a level that feels safe for you. However, if you do feel uncomfortable during the interview it can be stopped so you can have a break, and restarted when you are comfortable to continue. You can choose to withdraw from the research at any point up until two weeks after completion of your interview without giving a reason.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the lead researcher, or their supervisors, who will do their best to answer your questions and resolve your concerns. The researchers contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting Professor Olivier Sparagano, Associate Pro-Vice-Chancellor (Research) via email at: IRAS-sponsor@coventry.ac.uk. If you wish to complain within the NHS, you can also contact the Patient advice and Liaison Services (PALS) at Warwick Hospital via email: pals@swft.nhs.uk or telephone: 01926 600054.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice; all information about you will be handled in confidence meeting the requirements of the Data Protection Act 1998.

If you join the study, anonymised parts of the data collected for the study will be looked at by authorised persons from the research team. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

The individual interviews will be audio-recorded and transcribed. Transcription will be completed by the researcher, however if it is completed by a 3rd party, such as a professional transcription service, confidentiality will be maintained. All data will be kept securely either on password protected and encrypted usb sticks, computer drives or in locked filing cabinets.

Once audio-recordings have been downloaded on to a password protected and encrypted computer, the files will then be deleted from the recorder. The audio-files will be transcribed with all names and identifiable information removed to protect your identity. Once transcribed the audio-recordings will be destroyed. All data will be stored according to the Data Protection Act 1998 and will be kept separately from anything which identifies who you are. Once transcribed, your data will be used in Doctorate in Clinical Psychology thesis and may be used for publication. Your contribution will be anonymous and it is intended that where direct quotes are used your contribution will be unidentifiable and every effort will be made to ensure confidentiality, however this cannot be guaranteed. Data, including personal information such as your name, address and GP details, will be held securely at Coventry University for 5 years before being destroyed.

If you disclose information that means the researcher is concerned: for your safety, the safety of others or believes there has been malpractice by health professionals then confidentiality may be broken as the researcher has a duty of care to protect you and others. If this occurs the researcher will endeavour to discuss this with you but will also need to discuss such concerns with their supervisor and decide on the appropriate course of action; which may involve informing your GP or other relevant agencies.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you can withdraw from the study during a period of up to two weeks following the interview, without giving a reason. You can do this by contacting Ms Eleanor Gunn. It will not be possible to extract your data once the results have been analysed. Withdrawing will not affect any current, ongoing or future treatment you may access.

What will happen to the results of the research study

The results of the study will be written up as part of report which will go towards a Doctorate in Clinical Psychology which is due for completion in September 2018. If the project is put forward for publishing this is likely to be in a health-related, psychology or medical journal. You won't be identified when the project is written up or submitted for publication. If you would like a summary of the results then let Ms Eleanor Gunn, Trainee Clinical Psychologist know and I will email you a copy after this date.

Who is organising and funding the research?

This research is being organised by the University of Coventry and University of Warwick and is not receiving any funding. The research is being carried out by the Ms Eleanor Gunn, Trainee Clinical Psychologist at Coventry University and the University Of Warwick, Dr Sarah Simmonds, Senior Lecturer in Clinical Psychology, Jo Kucharska, Clinical Director in Clinical

Psychology and Dr Kirstie McKenzie-McHarg, Consultant Clinical Psychologist at South Warwickshire NHS Foundation Trust as part fulfilment of a Doctorate in Clinical Psychology.

Who has reviewed the study?

All research in the Coventry University is reviewed via a Research Ethics Committee, to ensure that participant safety and wellbeing is protected. This study has been reviewed by Coventry University Ethics Committee. Additionally it has gained NHS Health Research Authority approval provided by the East of England – ESSEX Research committee.

What do I do now?

If you are interested in taking part in the research or in finding out more about it, we would be grateful if you could complete the consent form and return this to Eleanor Gunn [REDACTED]. You will then be contacted by Ms. Eleanor Gunn, Trainee Clinical Psychologist, in order to complete the short screening questionnaire and answer any questions or concerns you may have. Following this, where appropriate an interview time and date will be set up. If you have any further questions about the study, please do not hesitate to contact me. Allowing us to contact you about the study does not mean that you have to take part.

Thank you very much for your time.

Eleanor Gunn

Further information and contact details

Researcher: Eleanor Gunn

Address: School of Psychological, Social and Behavioural Sciences,
Faculty of Health and Life Sciences
Coventry University
James Starling Building
Priory Street
Coventry
CV1 5FB

Email: [REDACTED]

Telephone: [REDACTED]

Supervisors:

Name: Dr Sarah Simmonds

Address: School of Psychological, Social and Behavioural Sciences,
Faculty of Health and Life Sciences
Coventry University
James Starling Building
Priory Street
Coventry
CV1 5FB

Email: [REDACTED]

Tel: [REDACTED]

Name: Jo Kucharska

Address: School of Psychological, Social and Behavioural Sciences,
Faculty of Health and Life Sciences
Coventry University
James Starling Building
Priory Street
Coventry
CV1 5FB

Email: [REDACTED]

Tel: [REDACTED]

Name: Dr Kirstie Mchenzie-McHarg

Warwick Hospital
Larkin Road
CV34 5BW

Email: [REDACTED]

Appendix O: Participant consent form



Consent Form

Title of Project: Women's Experiences of Primary Tokophobia

Name of Lead Researcher: Eleanor Gunn, Trainee Clinical Psychologist

1. I confirm that I have read and understood the information sheet dated.....
(version.....) for the above study. I have had the opportunity to consider the
information, ask questions and have had these answered satisfactorily.

☐

2. I understand that my participation is voluntary and that I am free to withdraw,
without giving any reason, up to two weeks after my interview date. If I withdraw this
will not affect my medical care or legal rights.

☐

3. I agree to my General Practitioner being informed of my participation in the study if I
meet the conditions in the participant information sheet and to them, or other
relevant agencies being contacted if there are any concerns about my safety or the
safety of others.

☐

4. I understand that the interview will be recorded and that anonymous direct quotes
from the interview may be used in the final thesis and any publication.

☐

5. I understand that anonymised relevant sections of my data may be looked at by the
research team and I give permission for these individuals to collect, access, store,

analyse and publish data gained from my participation in this study. I understand that my participation is confidential.

☐

6. I understand that recording of my interview will be destroyed after it has been transcribed. The transcribed data and other information gathered as part of the research will be stored securely at Coventry University for 5 years before being destroyed.

☐

7. I agree to take part in the above study.

☐

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

Appendix P: General Practitioner patient notice of participation



Dear XXXX,

Re: (Patient name, age, DOB and address of patient)

I am writing to make you aware that (insert participants name) has consented to taking part in research which aims to explore the experience of women who identify as having a of severe and disabling fear of childbirth called primary tokophobia.

(insert participant's name) has agreed to participate in an interview lasting approximately between 45 – 90 minutes, discussing this topic. The research has received Coventry University Ethical Approval and NHS Health Research Authority approval. The findings will primarily form part of a doctoral award in clinical psychology and may be published in future. Whilst no changes in (insert participants name) care are required to facilitate their participation in the research, I enclose a copy of the patient information sheet for your reference.

Please contact me if you have any questions about the research.

Yours sincerely

Eleanor Gunn

Lead Researcher and Trainee Clinical Psychologist

Appendix Q: Participant debrief information



Debrief Sheet

Study Title: Women's experiences of primary tokophobia

Lead Researcher: Eleanor Gunn, Trainee Clinical Psychologist

Thank you for taking part in the above study, your participation is greatly appreciated. You may find the following information useful.

Aims of the research

The research you have taken part in aims to explore women's experiences of severe and disabling fear of childbirth known as primary tokophobia to enable better understanding and knowledge about the condition. It is hoped that by providing more information and insight into the condition, that this may help services to better support women with primary tokophobia.

Sources of support

If you feel upset following participation in this project, we would encourage you to contact the principal researcher. They will be able to signpost you to the most appropriate form of support for you, their number is detailed below.

Researcher's contact details:

Lead Researcher

Eleanor Gunn, Trainee Clinical Psychologist

Coventry University

Priory Street

Coventry CV1 5FB

Email: [REDACTED]

Other sources of support you may find helpful include:

Your GP, they will be able to sign-post and refer you for support if required.

Mental Health Matters 24hour helpline provide emotional support and information for those in distress and are struggling to cope. Tel: 0800 616171

Samaritans provide support for people to talk about whatever is getting to them including those who are suicidal. Tel: 08457 90 90 90 * (UK)

NCT's helpline offers practical and emotional support in all areas of pregnancy, birth and early parenthood: Tel: 0300 330 0700. Website: <https://www.nct.org.uk/>

Tommy's provide information about pregnancy, including tokophobia and where to gain further support: Website: <https://www.tommys.org/pregnancy-information/im-pregnant/mental-wellbeing/specific-mental-health-conditions/tokophobia>.

The Birth Trauma Association provides information and support for anyone who is traumatised by childbirth: <http://www.birthtraumaassociation.org.uk/>

What if I wish to withdraw from the study?

You can withdraw from the study up until two weeks after taking part in the interview, without giving a reason. You can do this by contacting Eleanor Gunn (contact details above). In this instance, you can have the audio recording and transcription of the interview, along with your demographic details, removed from the study and destroyed.

What if I would like further information about the findings of the study?

If you would like further details of the study please contact the Lead Researcher (details above) , they will be able to provide you with a summary of the research after October 2018, once it has been completed.

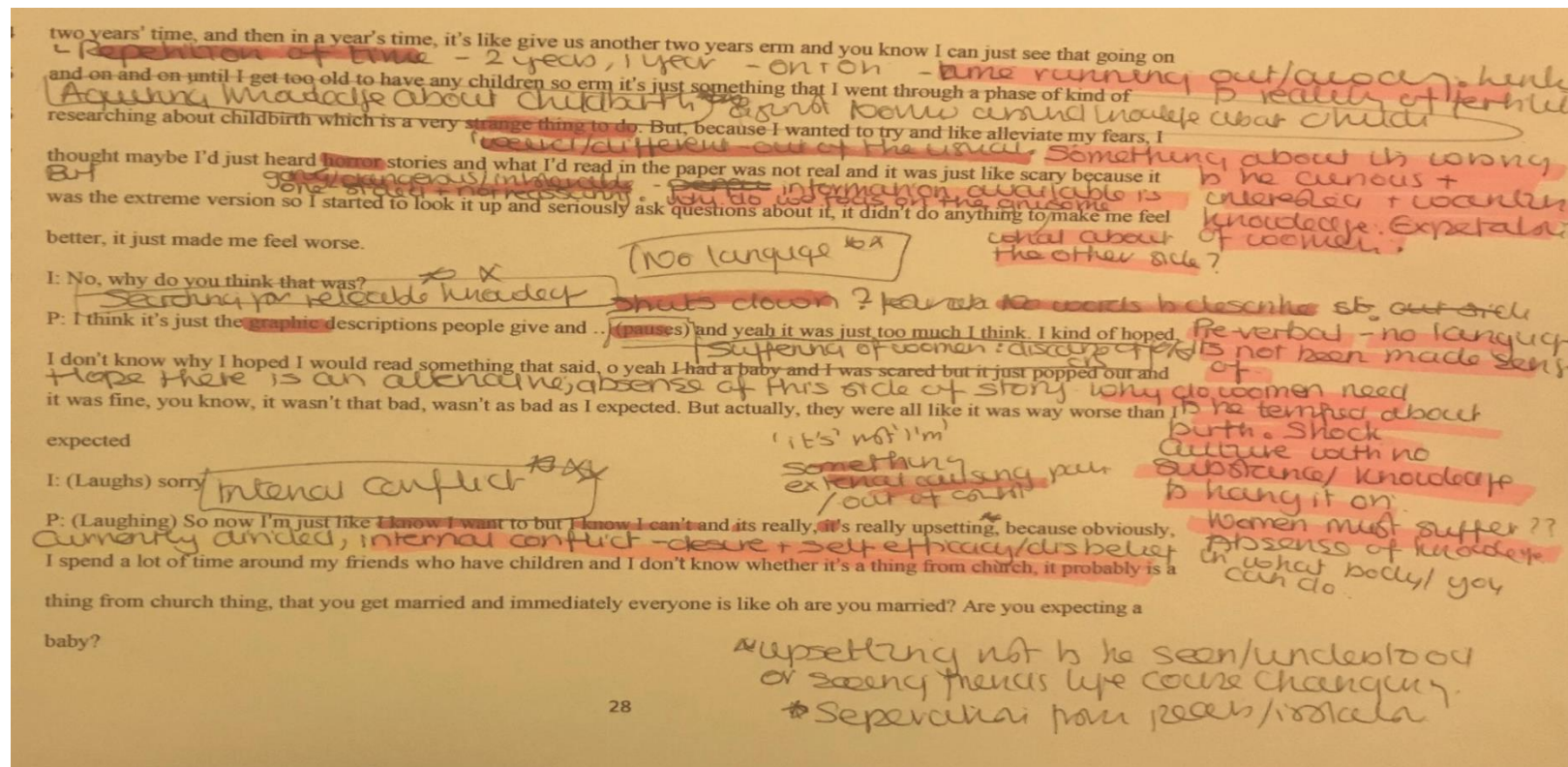
Appendix R: Interpretative phenomenological analysis procedure

Stage 1: Reading	The transcripts were read to familiarise the researcher with the content. During the initial reading the participants interview was listened to in order to ensure the participant became the focus. Initial observations were noted.
Stage 2: Initial noting	Initial noting of the transcripts was completed. This focussed on making descriptive, linguistic and conceptual annotations on the transcripts.
Stage 3: Developing emerging themes	The beginning of the transcript was returned to, with initial emergent themes noted. This included moving to higher levels of interpretation and linking the text to psychological concepts.
Stage 4: Searching for connections between emergent themes	Connections between emerging themes were identified. With similar themes being clustered together. During this superordinate themes started to emerge.
Stage 5: Moving to the next case	Stage 1-4 were repeated for each transcript. Attempts were made to bracket the analysis of the previous transcript to enable new themes to emerge from each case.
Stage 6: Looking for patterns across cases	Themes were looked for across cases, by laying out the sub-themes identified by each case and organising these into superordinate themes. This was an iterative process, with themes being reconsidered and relabelled.

Adapted from Smith et al. 2009

Appendix S: Examples of transcript coding

Excerpt from Scarlett's transcript illustrating coding process



Excerpt from Laura's transcript illustrating coding process

85 I: ok

86 P: because I just did not want a single person—even our family erm—but we we did tell people, I had to tell work anyway

87 erm and that kind of was the sort of the spiralling start I think, erm cause straight away people are asking you things people

88 are commenting and they just felt so exposed [pause] I think, I hated the fact that people would looking at me or I'd assume

89 everybody was looking at me, erm [pause] I questioned—I just—I had an anger, I felt angry constantly, really angry, erm

90 because, I found it so intrusive if somebody would ask me "oh are you planning to breastfeed" or you know "are your boobs

91 feeling sore" I wanted to hit people. Erm [baby crying] ah you're okay".

92 Erm yeah, I found, especially once I started to show a bit erm I don't know, I don't know what it was, the hugest thing for me

93 was the body thing, the changing—my changing body. I couldn't stand it erm I couldn't stand the fact that obviously

94 everybody knows how your body changes in pregnancy so there was no hiding from it

95 I: okay, so what cause people could see the changes

96 P: yes and just their general knowledge and education round pregnancy, so they knew that your boobs get different and so

97 they felt it appropriate to ask me, you know, just all sorts erm—and I couldn't stand it er I would lock myself away in the

98 toilets at work, erm I would snap at people erm [pause talking to baby] even I would worry about asking me how I was

99 feeling or anything like that really did not erm, didn't like the lack of privacy I got with it and just generally I hated being in

100 my own body it was such a surreal feeling of not being able to escape something.

101 I: yeah

Exposure + vulnerability of pregnancy.

Invasion of boundaries

Social intrusion of boundaries

Body ownership

Social intrusion of boundaries

Body is no longer private

Body no longer private

Changing ownership of body

Body becomes everyone's, public property. speaking about parts of the body normally people wouldn't.

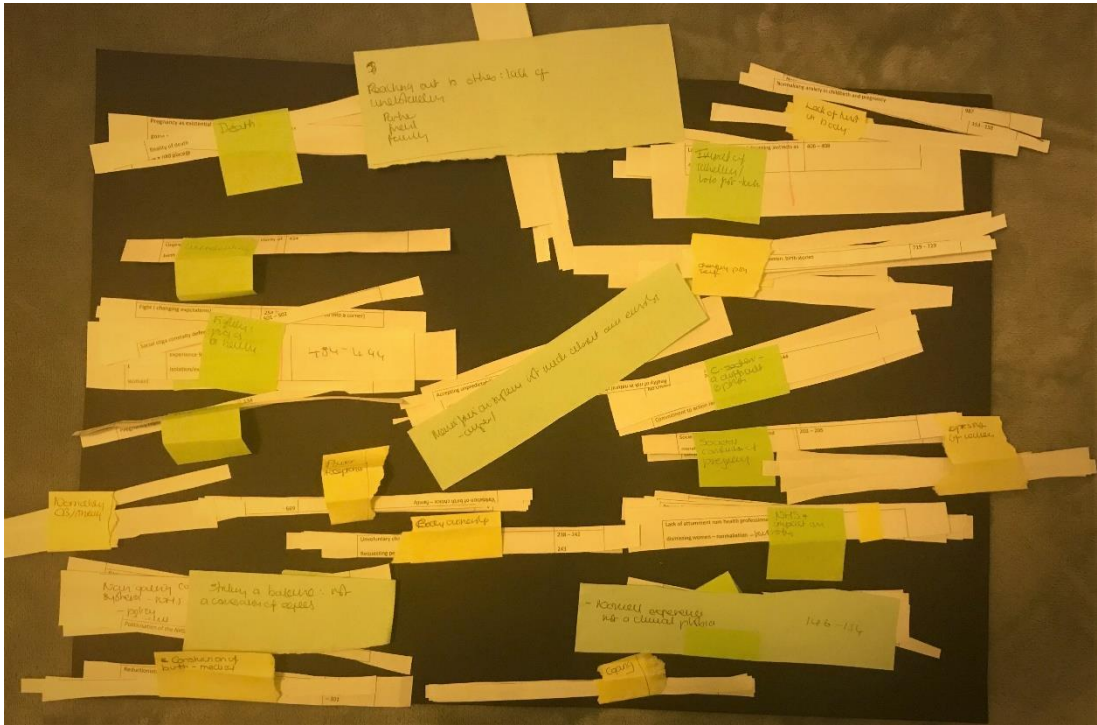
Reflects of changes others seeing body as hers. Taking back ownership

Pregnancy as a trap. One started and stop - pregnancy, childbirth, motherhood.

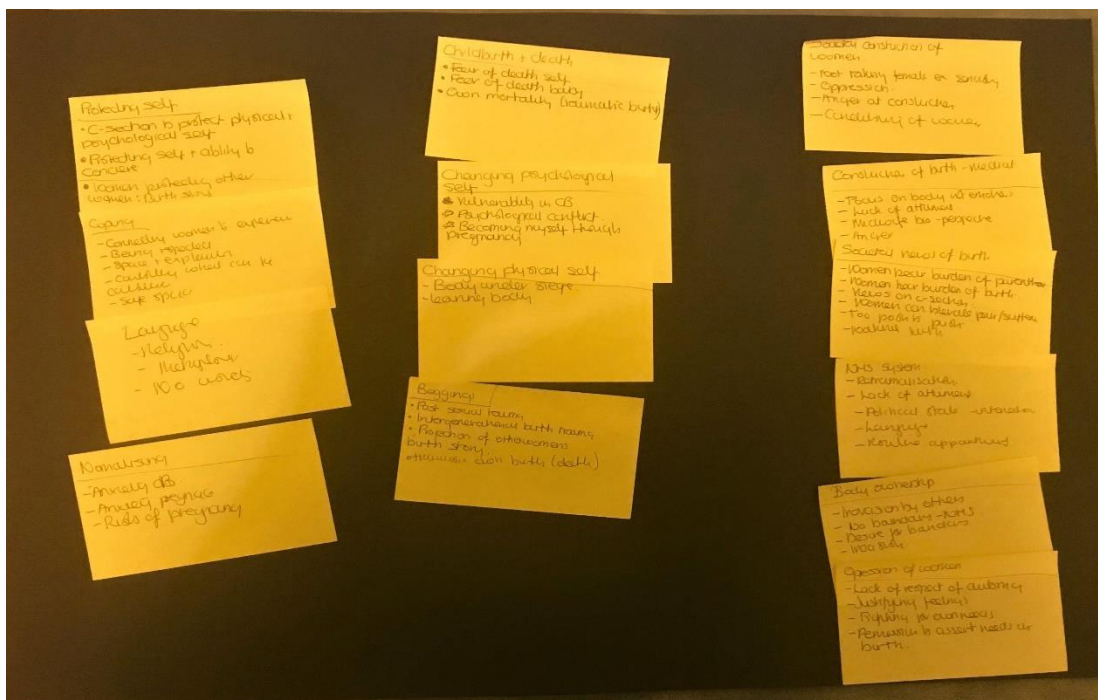
Changing body desire to escape

Appendix T: Process of theme development

Example of grouping emergent subthemes across interviews:



Example of developing emergent superordinate themes:



Appendix U: Example of respondent validation

Email sent from participant on 3rd April 2018 at 10:45

Hi Eleanor,

Thanks so much for sending this through - I have been thinking and wondering about your research! I think you've done an amazing job of distilling some kind of sense out of the stream of consciousness I unloaded on you, and it's interesting that people's experiences were presumably congruent enough for you to be able to do this. Of course the detail may be different and I will be really interested to read the final copy in due course. I'd love to know to what extent people also assign meaning in a similar way, given that the themes are similar.

And yes thank you, I am very well - I hope you are too!

Best of luck with the final stages of your research,

Emily

Emilys comments on each theme:

Theme 1:

****** Yes - for me it wasn't physical death but rather "lifestyle" issues such as disability (for both of us) and incontinence/prolapse (for me). But in a metaphorical sense there was a strong sense of facing a death-like experience and re-birth, and that I had both failed to live up to this challenge) - and had bottled out of a potentially transformative experience. That is a major reason why I considered a VBAC the second time around when the anxiety was so much reduced by the knowledge I had a free choice - but rationally I'm so glad I had a second CS!

Theme 2

** Yes yes yes - I so strongly agree with this. This theme added very significantly to my subjective experience of isolation (1. it was hard for my male partner to understand why I would feel these pressures so much given that I disagreed with them on a rational level; and 2. I found it very hard to trust HCPs as I wasn't always sure when their advice was driven by clinical evidence and when it was driven by values), and obsessiveness (I had to keep picking over the details by myself). I acknowledge that a lot of people would think it is desirable that the NHS reflects societal values to some extent. Also, it was hard to discuss the whole topic with HCPs as there I felt there was confusion between evidence and values and you can't always start a conversation by trying to unpick this first!

Theme 3

** Yes, agreed.